AN INVESTIGATION TO DETERMINE THE APPROPRIATENESS OF CARE PROVIDED BY CHILDREN FOR PHYSICALLY DISABLED PERSONS

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DEDICATION

To the young carers who participated in this study and all the other young carers.

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My sincere thanks to:

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ABSTRACT

The area of young persons caring for the physically disabled is a relatively new field of research. In South Africa, limited attention has been devoted to adult carers; young carers have not been addressed. In Britain, the role of young carers has been highlighted in the course of several research projects.

The aim of the present research project was to investigate via the exploratory research methodology, the appropriateness of children caring for physically disabled pesons.

The current caseloads of the Association for the Physically Disabled (Western Cape), and its branches were used for the purpose of this research. 231 cases were identified, with 470 children between the ages of 6 and 18 years inclusive.

Random sampling was used to select 46 cases consisting of 72 children. At the time of the administration of the interview schedule, only 65 respondents were available. A kilogram scale was used for measurement.

The following variables defined inappropriate care: type of caring activities, time, weight and age.

The type of caring activities refer to an inappropriate activity for a young carer, for example, assisting the physically disabled person with toileting. In terms of time, the researcher set the baseline for inappropriate caring to be in excess of 4 hours caring per day. In terms of weight, the researcher established that a person could only comfortably pick up half their weight on a regular basis. Age appropriateness was also assessed using activities, for example, a 7 year old changing her mother's sanitary towels, this is inappropriate because this child has not yet experienced menstruation.

The researcher also looked at replacement activities which could previously have been or should be done by the physically disabled person.

The data gathered was analyzed with the use of graphs, pie charts, histograms, tables and short discussions.

The results proved that young carers, are definitely involved in inappropriate caring, in terms of type of caring

activity, time, weight and age, for the physically disabled.

It is recommended that young carers receive guidance and assistance with regard to caring for the physically disabled. The researcher has made several recommendations to professionals and the various social service organisations, in the form of seminars, a central register to identify young carers, an improved attendant care allowance schemes and expansion of care attendant schemes, to mention just a few.

It is concluded that the plight of young carers needs to be highlighted and that service organisations should heed the recommendations this research document has outlined.

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CHAPTER ONE

1. INTRODUCTION

1.1 STATEMENT OF THE PROBLEM

This document is an investigation to assess the appropriateness of children caring for the physically disabled. The term 'children' refers to any child between the ages of 6 and 18 years who lives in the home of the physically disabled person and who is involved in the care of that person. It does not necessarily have to be a family member it could be a neighbour's child sleeping with the disabled person at night. In the ensuing chapters the researcher will sketch the context of this type of caring by examining the international arena in relation to the local perspective with regard to the care of the physically disabled.

According to Singer and Irvin (1989) and Inskip (1989) the shift in the United States and Britain from institutionalized care to community care has received a significant amount of attention. Community care in this

instance refers to family care. In South Africa, for the majority community care is not a new trend but the norm. This is primarily as a result of inadequate provision of special schools, day care facilities and institutions for the physically disabled. Central figures in community care are the family members. In the United States and England, to name just two countries, ways and means were devised to make the task of these families more manageable, this aspect will receive further attention in chapter two of this document (cf. 2.2.1 : 10)

The focus has been primarily on the individual disabled person/family member for services provided by welfare organisations in South Africa. The family is usually solicited to meet the needs of the disabled person and welfare organisations have tended to advocate support groups for parents of disabled children.

More recently the term 'carer' has gained momentum with regards to parents and other adults caring for the disabled. These carers automatically become unpaid workers who are saving the social service provider's money. In many cases, wives and mothers have had to give up their jobs to care for the physically disabled person; those who could

not afford to give up their jobs have had to rely heavily on their children to take care of the disabled person. In instances where a parent is disabled, a similar situation arises. The other parent is concerned with providing an income and the child has to step in as a carer.

This job of caring may come about suddenly due to an accident, or gradually as a result of a disease. In South Africa, social workers are aware of cases where children are carers, but they are unable to speak authoritatively about how many such children there are, the types of caring they are involved in, and whether or not such caring can be considered to be appropriate for a child.

For the purpose of this research children between the ages of 6 years and 18 years inclusive, will be referred to as young carers. The researcher established that adult carers have received attention in a previous research paper (Thomson, 1983) to recommend the initiation of a Care Attendant scheme (cf. 2.7.2 :30). As far as the researcher is aware, specific research on young carers has not been done in South Africa, thus far.

Exploratory research (cf. 4.1 :45) was undertaken prior to more explanatory research, because the young carers who the

researcher initially encountered appeared to be involved in caring that was considered by the researcher to be inappropriate in terms of the types of activities and the amount of time spent on these activities. Bearing all this in mind the researcher set out to identify the number of young carers involved in inappropriate caring.

The researcher would like to point out that, short of the identifying particulars of the physically disabled person in the interview schedule, no further attention is paid to them as they are not the focus of this research.

This research does not seek to abolish the occurrence of young carers and also does not seek to encourage it. Rather it aims to assess the extent and appropriateness of the caring being done by young carers. The assessment will be done in terms of type of caring activity, time, weight and age.

When the researcher refers to types of caring activities, it could be assisting the physically disabled person with toileting, to mention just one type of caring. Time, for the purpose of this research refers to the hours spent caring for the physically disabled person whether it is per day, per week or month. Too many hours spent caring would

be considered to be inappropriate, further discussion on this aspect follows in chapter two (cf. 2.8.4 :36). Then there is also the weight issue and this refers to activities such as the lifting of the physically disabled person by the young carer. The weight difference between the young carer and the physically disabled person has considerable bearing on this issue. Finally, the age variable is significant with regard to certain activities, for example it is considered to be inappropriate for a 7 year old to change his/her mother's sanitary towels while she is menstruating.

There are also other activities that young carers are involved in. These relate to household chores that would previously have been done by or should be done by the disabled person. The researcher is aware that it is generally accepted, in our society that children assist with household chores. But these chores are seen as additional hours of being "on duty". The nature/extent of inappropriate caring is based on the literature, the local professionals' opinions and the researcher's opinion. The researcher is of the opinion that young carers in the Western Cape and its immediate rural areas (cf. 3.2.2 : 41) are inappropriately caring for the physically disabled. In

1.3 OUTLINE OF THE FOLLOWING CHAPTERS

Chapter 2 : The literature review focussing on the concepts of the research from an international perspective. The researcher also examines the local perspective. The available literature and the Association for the Physically Disabled (Western Cape) and its branches functioning in this field will be examined.

Chapter 3 : The objectives, scope and limitation of the research will be stated in this chapter.

Chapter 4 : This chapter will look at the research design and methodology.

Chapter 5 : In this chapter the data will be analyzed and the findings will be discussed. Graphic representations : graphs, histograms, pie charts and short discussions will be used to present the findings.

Chapter 6 : The recommendations will be made to the relevant professional and organisations. The researcher will then end off this document with a few concluding remarks.

CHAPTER TWO

2. LITERATURE REVIEW

In this chapter the researcher will present issues and definitions relevant to this research, as found in a variety of international books, research reports and journal articles.

The review will provide an overview of the general field of physical disability, before addressing the specific problem which forms the central focus of this paper, namely that of the activities of young carers:

2.1. Physical disabilities and social work services
2.2 Community-based care
2.3 Carers
2.4 Young carers
2.5 General literature

2.1 PHYSICAL DISABILITIES AND SOCIAL WORK SERVICES

2.1.1 Oliver (1983 : 38) defines physical disabilities as:

> Impairment : lacking all or part of the limb, or having a defective limb, organ or mechanism of the body. Disablement: the loss or reduction of functional ability. Handicap: the disadvantage or restriction of activity caused by the disability.

Oliver (1983) further presents the framework for the social model approach as a new form of social work intervention with the physically disabled. He compares it to the traditional model, the individual model, which sees the problems experienced by the disabled people to be as a direct result of their disability. The task of the social worker in this instance is to help the physically disabled individual through the adjustment phases of shock, denial, anger and depression.

The social model was initially introduced by Finkelstein (a disabled person) who sees the problems of adjustment as not being for the physically disabled individuals but rather for society, for example the environment disables because it is not accessible.

2.1.2 Jefferys (1969 : 3) defines physically disabled persons as:

> ... people who have some severe limitation of physical capacity ... due to motor limitation of some kind, or it may be that other organs of the body like the heart and lungs may be implicated and this may impose severe limits ...

The writer devotes the rest of this document to the physically disabled individual in the community as opposed to the physically disabled person in some form of institutionalized care.

2.2 COMMUNITY-BASED CARE

2.2.1 Powell and Hecimovic (1981:6) define the physically disabled person as having "... a physical impairment or combination of mental and physical impairments". They focus on respite care and community-based services to the disabled and their families. Six different types of respite care which are being offered to families in the United States are discussed:-

a. at home respite care;

b. special respite care homes;

c. special respite care facilities;

d. day/night respite care service;

e. respite programs based at an institution and

f. respite care co-operatives.

These authors also recognise that the disabled living at home in the community is a reality but they also recognised "... the strain of these demands ..." on the family. They also cite that 40 hours caring per week for a severely physically disabled person as a reason why there is a high turnover of care staff at institutions in America (Powell and Hecimovic, 1981:13). They refer to the community and social workers as being in a transitional state with the final destination being integration of the physically disabled person into the community. The writers also comment that the problem of replacing the person's activities could involve increasing cost and time.

2.2.2 De Jong (1981) did a study to indicate that certain factors will hamper the physically disabled person in his acquisition of independent living. A variable he uses is 'in-home assistance' which (De Jong, 1981 : 116):

> ... comes in a variety of activities such as assistance with personal care (e.g. bathing, grooming, dressing, toileting), meal preparation, light housekeeping (e.g. laundry, cleaning), shopping and supervision of children.

He asserts that if these needs are not met then the person will be limited in trying to participate in work and extra-mural activities. De Jong (1981: 145) also makes the following statement :

> ... the sex of the spouse was an important consideration: males (physically disabled) with female spouses could depend on more regular care.

He also stresses the need for expansion of the care attendant schemes because a large number of respondents were not receiving adequate in-home assistance.

2.2.3 Inskip (1981 : 1) explores existing family support services and makes recommendations for initiation of further family support services. These services provide:

> ... personal care and help for physically and mentally handicapped people living in their own homes ...to alleviate stress in families and enable disabled people to continue to live at home ...

This booklet further explores training attendants and suggests a framework for a care attendant project. Inskip (1981 :3) defines caring activities as follows:

> ... getting the client up and putting him to bed, washing hair ... collecting their pensions, letter writing and making telephone calls, ... sitting and listening ...

2.2.4 Singer and Irvin (1989 : 45) have looked at supporting 'caregiving' families in a variety of ways. These writers felt that families who have severely disabled family members:

> ... face common challenges, including chronic stress, grief, financial costs and losses in financial opportunities, extraordinary time demands, difficulties with normal family routines, marital discord, absence of services and difficulties with physical management of the child.

They advocate that there should be formal 'caregivers' who are on a state- aided programme.

2.3 CARERS

2.3.1 In March 1980, a survey report (Equal Opportunities Commission, 1980 : 6) looked at the problems and the needs of carers. A postal survey was conducted in 1978 in West Yorkshire in

England. Questionnaires were sent to 2500 homes and 909 responded. Of these respondents 116 were interviewed in-depth.

Caring was considered to be a full-time job by the majority of the carers. One of the problems which this booklet emphasises is the most common health problem incurred by carers which is (Equal Opportunities Commission, 1980 : 20):

> ... bad backs and bad legs brought on by lifting dependents in and out of bed, in and out of the bath or up and down steps.

Of the 116 carers interviewed 75% were females. (Ibid, : 7).

2.3.2 The research report of the Equal Opportunities Commission (1982 (a) : viii) asserts that the term 'carer' is perhaps not the most sactisfactory term for "...people caring for dependents on an unpaid basis." and this is seen as an indicator of the "... lack of social awareness regarding this role." The research report also states that carers are usually considered to be an informal caring network. The document quotes the Crossroads Survey, which was the proposal for a care

attendant scheme which indicated, that, of the 42 adult carers interviewed, the greatest number spent between 4 and 6 hours caring per day. These carers all indicated that they needed help. (in Equal Opportunities Commission, 1982 (a) :14).

2.3.3 In the booklet, Who Cares for the Carers (Ibid (b) : 1), caring is seen as:

> ... an open-ended task which grows more onerous over the years ... caring is very much a full time job.

The recommendations of the Equal Opportunities Commission (1982 (b)) look at the concept 'care in the community'. The principle source of care is the family.

Two additional types of community care are addressed: unremunerated care provided by women volunteers and then a more organised care attendant scheme which is also provided by predominantly females who receive a small amount of money. This study recommends that the carer's needs must be met with regard to home help, relief care, day-care centres and hostels, domiciliary health services, accessible housing

and assistive devices to make the caring easier, for example, a taxi-commode for toileting the physically disabled person.

2.3.4 Pitzele (1986 : 151) prefers the term 'caregiver' and defines it as :

> ... any person who takes primary care of another person, either permanently or temporarily.

Pitzele (1986) also comments that the relationship between the carer and the disabled person is one for which there has been no planning. Caring can be (Pitzele, 1986 : 156) :

> ... difficult and exhausting ... and may range in a single day from doing the wash or cleaning up a bowl of spilled soup to giving a shower or removing a bowel impaction. .

2.3.5 Pitkeathley (1989) documented the plight of carers, their role and their needs. She directs her book at the policy - makers in England and recommends a better state remuneration for carers. She says just as the physically disabled need day-care, carers also need short-term relief and attendant care.

Carers also need support organisations, carers'

centres, time off, home help, laundry services, transport services, counselling services and volunteers to do sitting services. The counselling services are necessary she says for the carers to deal with any feelings, such as anger, guilt, to mention just two. Pitkeathley (1989:11) defines a carer as :

> ... someone whose life is in some way restricted by the need to be responsible for the care of someone who is mentally ill, mentally handicapped, physically disabled or whose health is impaired by sickness or old age.

She also adds that the majority of carers will be living with the person they are responsible for. Caring activities vary from situation to situation according to Pitkeathley (1989). She says that caring is time consuming but more importantly, it requires skills, for example, many adults do not have the expertise to insert a catheter, give a injection and manually evacuate the bowels.

With regard to the concept of 'young carers' Pitkeathley (1989 : 24) says the following:

> ... responsibility falls on the child ... until she finds herself washing and dressing a parent before school, rushing home at

lunchtime to prepare food or take the parent to the lavatory, as well as taking responsibilty for the rest of the household.

2.4 YOUNG CARERS

2.4.1 In 1987, the Tameside Research was carried out in the abovenamed Borough, near Manchester, England. Two surveys were carried out: the first constituted a screening survey; the second a follow-up interview with all those who identified themselves as carers. This research was not directly geared towards young carers. From the age groups identified in this study, the researchers were able to ascertain that young carers as primary carers were not a common occurrence. Only 0.14% were identified as primary carers while 13% of the young carers were peripheral carers (Meredith, 1990:1).

The Tameside Research raised many issues and heightened the community's awareness with regard to the actual existence of young carers (Ibid).

2.4.2 As a follow up to the issues raised in the Tameside research, an investigation was conducted

in the Sandwell Borough Secondary Schools to assess how many young carers there were in this area. The focus of the research was the (Social Services Research, 1990 : 32) :

> ...school-aged carer who is taking some responsibility for the care of a sick or handicapped relative ...

Ninety-five young carers were identified as a result of a questionnaire sent to the schools. The findings showed that fifty-seven carers were female and thirty-seven were male. The largest number of carers (37) were found in the 14-15 age category: the second largest number, 22 carers were in the 13-14 age category. (Ibid, : 34).

The Sandwell research project examined school-going children of 11 years and older. The study found that young carers were more at risk when the mother is incapacitated because of the major role she plays in a family.

They found that 50 young carers were responsible for their mother and only 14 for fathers. The

remaining 31 respondents cared for others, for example siblings, grandparents or friends (Ibid : :34).

2.4.3 White (1989 : 23) defines young carers as:

> ... young people in their early teens or younger, providing physical and emotionally draining care for their parents - including every intimate act of personal hygiene.

The writer comments that if adults have problems being carers then it is extremely thought-provoking to imagine the emotional burden to a 10 year old caring for a mother. White (Ibid : 42) also describes the following caring tasks which young carers are involved in:

> ... getting up several times at night to turn a parent in bed to avoid pressure sores or rushing home from school at lunchtime to give life saving insulin injections ... washing, bathing, dressing, toileting, feeding and the household tasks of preparing meals, shopping, caring for younger children, cleaning, managing the household budget ...

White (Ibid : 42) quotes Ashley, a British member of Parliament who reacted to a 11 year old boy changing his mother's sanitary towels during her periods by saying that its "... a stain on British society and a scandal." White (Ibid) says that despite the shock reaction there are still

local authorities in England, who do not offer home help or home care to households of disabled persons where there is an able-bodied person of 12 year and older.

2.4.4 Fallon (1990 : 22) comments that it is not unusual for a young carer to start caring from 05h30 and also for a young carer to spend more than 35 hours per week caring. Fallon (Ibid : 21) cites a case where an eight year old had to take total care of her severely disabled mother and a five year old brother. The writer cites the nineteenth century Royal Commission quote (Ibid : 22) :

> ...heavy work was not appropriate for young people whose bones were growing and developing.

This writer asserts that the continuous lifting of a physically disabled person and pushing a wheelchair can lead to serious health problems, particularly back problems.

2.4.5 Lunn (1990 :10) defines young carers as :

> ... those children who by force of circumstances find themselves looking after a dependent adult.

Lunn (Ibid) asserts that on the basis of a recent survey conducted in Britain by the Carers National Association there could be ten thousand young carers who are primary carers and under the age of 18 years.

2.4.6 Meredith (1990 : 9) says that caring often has a devastating effect on a "... child's social, personal and educational development." He also describes excessive and inappropriate caring as being too much to soon in a child's life and creates a sense of false maturity. The young carer in some instances, assumes the full control of the family's domestic situation and has too little time for important childhood activities. Meredith (Ibid) writes about his concerns for the young carers health, because injuries :

> ... such as back injuries can arise from the tasks like pushing wheelchairs and turning a person in bed.

He suggests that there should be plans for formal respite, for example, befriending services and support schemes to give children a break from the stress so that they can experience ordinary

family situations.

2.5 GENERAL LITERATURE

The researcher also reviewed general literature with regards to children's needs and the weight issue.

2.5.1 Brunner et al (1976) advocates the importance of play and stresses that the need differs with the different age group. A six year old may want to play the whole day whereas the 16 year old leisure activity could be confined to a specific activity such as going to the cinema, a disco or reading a book. The writer does not specify exact times required for this activity in the different age groups.

2.5.2 Cameron and Skofronick (1978 : 21) allude to the damage which is caused to the back through regular incorrect lifting :

> ... lifting heavy objects ... is a primary cause of lower back pain ...

An example is also graphically presented to show the effects of lifting, on a person weighing 40

kilograms picking up a weight of 20 kilograms incorrectly. They advocate that a person could pick this weight up more easily if using correct posture but continuous lifting and bending over to pick up a heavy object will develop large "forces" in the lower spine which could eventually lead to a crushed vertebrae.

2.5.3 Pringle (1974) examines the needs of children, more specifically the need for balance and structure with regard to home life, education and social development. A section of this book is devoted to the functions of play and school and its related activities.

The researcher has reviewed all the literature and will now draw out the relevant aspects.

2.6 DEDUCTIONS DRAWN FROM THE RELEVANT LITERATURE

On the basis of the literature reviewed, the following may be deduced:

2.6.1 The term 'physically disabled' refers to persons with a permanent loss or reduction of functional

(motor) ability: this could be combined with a mental impairment. (cf. Jeffries, 1969; Oliver, 1983 and Powell and Hecimovic, 1981).

2.6.2 The literature indicates that the physically disabled need family assistance in order to cope and strive for a measure of independence. (cf. De Jong (1981) and Powell and Hecimovic (1981))

2.6.3 Where the physically disabled person resides in the home family members require some form of assistance to relieve stress and give them time to do other things. Care attendant schemes and a variety of respite/relief care schemes were outlined and presented for examination. (cf. Inskip, 1981; Pitkeathley, 1989; Powell and Hecimovic, 1981; Singer and Irvin, 1989).

2.6.4 Carers are identified as people who care for the disabled and all their needs. This caring is time consuming and hard work. (cf. Equal Opportunities Commission, 1980; 1982 (b); Pitkeathley, 1989; and Pitzele, 1986).

2.6.5 Doubt exists as to whether the term 'carer' is sactisfactory to really define the situation. (Equal Opportunities Commission, 1980 and Pitzele, 1986)

2.6.6 Females form the majority of carers. (Equal Opportunities Commission, 1980).

2.6.7 Young carers are defined as children who are forced by circumstance to look after a dependent adult (Lunn, 1990)

2.6.8 Young carers are involved in personal, initimate activities for adults. (Inskip, 1981; Pitkeathley, 1989 and White, 1989)

2.6.9 Young carers as primary carers are not the norm. Peripheral young carers are very common. (Meredith, 1990 and Social Service Research, 1990)

2.6.10 Females are the most prominent young carers. In instances where the mother is incapacitated, young carers are more at risk because of the role the mother plays especially with regard to the

replacement activities. (Fallon, 1990; Social Services Research, 1990 and White, 1989)

2.6.11 Young carers are involved in inappropriate caring in terms of type, time, weight and age. (Fallon, 1990; Meredith, 1990; Pitkeathley, 1989 and White, 1989)

In the following section the local perspective will be addressed.

2.7 THE LOCAL PERSPECTIVE

2.7.1 THE ASSOCIATION FOR THE PHYSICALLY DISABLED (WESTERN CAPE) AND ITS BRANCHES

The Association defines its clientele as "... persons with locomotor handicaps ..." (cf. Appendix 1 : 122). The researcher refers the reader to the Constitution of the organisation for its objective and structure (cf. Appendix 1 : 122). The branches will receive further attention in chapter three (cf. 3.2.2 : 40).

Additional local branches of the Association for the Physically Disabled are the Disabled Servicemen's Aftercare Association; Headway; Huntington's Society;

Ocean View Work Group; Tembaletu Day Care Centre; Volcare and Wallace Anderson Home.

2.7.2. THE SERVICES

Casework, counselling services form the most significant component of the services rendered by the Association. In the Annual Report of 1990/91, 1680 people received counselling services. These services include home circumstances investigations, application for disability grants, adjustment to the disability, housing adaptations, after-care services, family support, support services for the physically disabled person, assessments and referrals to: orthopaedic clinics, special schools, social groups, home industries, sport, rehabilitation centres, protective workshops, independent living centre and the attendant care scheme.

There is a close working relationship between social workers and hospitals, orthopaedic clinics, special schools and protective workshops to mention just a few of these referral sources. The social group, transport facilities, sport activities, rehabilitation centre, care attendant scheme, loan of appliance, education

bursaries, home industries, protective workshops and the independent living centre are all services provided by the Association for the Physically Disabled (Western Cape) and its branches. The social workers are also central to all the community projects, for example swimming groups, camps for physically disabled children and toy libraries and stimulation groups.

The researcher would like to focus attention on a few services which have direct implications for carers. There are support groups for parents locally and in the rural areas. At the head office there is a carer's group which is directed at adults. Other forms of assistance for carers are : transport facilities, the care attendant scheme and the independent living centre.

In 1983 Thomson conducted research (cf. 1.1 : 3) and a care attendant scheme was initiated. This study investigated the personal care needs of the severely physically disabled. 23 carers were interviewed to assess how much time they spent on the personal care needs of the physically disabled. Help with personal care activities was requested by all the physically

disabled respondent in the study and not all the carers felt that help was necessary.

The Association's Care Attendant Scheme offers relief to 36 families for one and a half hours per week day. The co-ordinator of the scheme does not allow any of her 5 male attendants to bath the disabled client when they are alone because back injuries have already been incurred by two attendants over the past 5 years. Only male attendants are employed therefore only male clients are receiving this service.

The Bromilow-Downing Independent Living Centre offers advice on adaptations to homes and assistive devices to make the physically disabled more comfortable but more importantly to make the task of the carer more manageable. Seminars are also presented on issues related to independent living. The Annual Report of 1990/91 reflects that 1951 people have been given advice and information during the 1990/91 financial year.

The above has provided a brief overview of the services of this organisation. For the purposes of this paper,

the organisation is significant in that cases of this organisation were utilized for the purposes of this research.

2.8 RELEVANT DISCUSSION

2.8.1 The relevant discussion will be with regard to the local and international perspectives and professional opinion. Young carers represent a new field which up until now has not received attention from the local service delivery organisations, as far as the researcher is aware.

Services are rendered to maximise whatever functional abilities the disabled person has left. After many months in hospital the person is released into his/her family's care. Although after-care services are rendered, their focus is usually the disabled person. The international writers have placed a familial relationship between the young carers and the physcially disabled persons. The cases of the Association indicate that as a result of the lack of suitable housing, a number of (biologically) unrelated

families may share a home. The term physically disabled person in this research does not necessarily reflect parents but disabled children as well.

As already stated the newness of this field has made it impossible for the researcher to focus on secondary school-aged children only (as was the case in Sandwell's research). The researcher used all school-going children ranging from 6 years to 18 years inclusive.

In addition, caring varies from case to case (Pitkeathley, 1989). The researcher is of the opinion that caring varies depending on the severity of the physical disability. A quadraplegic who has lost the use of all his limbs would be totally dependent for all his/her needs. A paraplegic would at least have the use of his/her arms and certain activities such as transfers to and from the wheelchair and even preparing meals will be within the person's coping means. Bi-lateral arm amputees, multiple sclerosis and TB Spine clients to mention a few

would also require most of the caring activities to be done for them. (cf. Appendix 2 : 135)

2.8.2 APPROPRIATE CARING ACTIVITIES

The researcher agrees with all the international sources of literature which presented several types of caring activities. She would like to add the following caring activities which the sources of literature have not mentioned: assisting someone else with the lifting of a physically disabled person, assisting the person with walking,brushing of teeth and hair, fetching things for the person, talking to the person, opening doors, playing games with the person, pushing the wheelchair and washing the person's clothes.

Appropriate caring activities for children in the researcher's opinion are the following: going to the shop, fetching water so that the disabled person can take their medication, brushing of hair and teeth, talking and listening, letter writing, making telephone calls, playing games, opening of doors, making tea and sandwiches and washing of the person's hands and face.

2.8.3 INAPPROPRIATE TYPES OF CARING ACTIVITIES

Some of the caring activities mentioned previously include activities which could prove to be problematic for the young carer. Fallon (1990) and Pitkeathley (1989) have mentioned different types of inappropriate caring. The researcher would like to mention a few additional inappropriate types of caring activities: toileting, bathing, emptying urine bags, fitting condoms and changing sanitary towels. These activities are a source of embarrassment for the children and are considered by the researcher to be inappropriate for them. The sight of blood can also be very frightening and damaging to a young child changing his/her mother's sanitary towel.

2.8.4 INAPPROPRIATE CARING IN TERMS OF TIME

Meredith (in Childright, 1990), Pitkeathley (1989) and Thomson (1983) all agree that caring is time consuming.

The Crossroads Survey (in Equal Opportunities

Commission, 1982 (a) : 5) indicates that carers who spent 4 to 6 hours caring per day needed help. The researcher considers more than 4 hours per day; 28 hours per week and 112 hours per month of caring by a young carer to be inappropriate.

Levett, a child psychologist at the Child Guidance Unit of the University of Cape Town suggests that there should be a balance of how a child's time is utilised. It is not easy to pin down specifics but generally it is accepted by other professionals and the researcher that a child should have 8 hours sleep and depending on their age, spend 4 to 7 hours at school. If the child then spends 4 hours caring he/she might just have time for one or two of the following essential activities, such as eating, bathing, dressing, homework and play. The Services Manager at the Parent Centre in Claremont, Cape Town advocates that a child should have at least 2 to 3 hours leisure time (depending on the child's age) which could be used to play with friends or on their own or in any other leisure activity.

Local teachers in the Western Cape advocate that at least 1 to 2 hours should be spent on homework for primary school children, who receive homework, and a minimum of 3 hours for senior school children. The Treatment Director of Leliebloem House Children's Home in Athlone, Cape Town describes the programme they have for school-going children as follows: 1 hour of homework for all ages and an extra hour for children from standards 5 to 10. The programme also makes allowance for 2 hours leisure time for the older children and 3 to 4 hours for the younger children. Levett of the Child Guidance Unit does not advocate a specific time for homework but normally tells parents and children that there should to be time for homework. The parent and the child should negotiate the time required depending on the standard the child is in. There are so many opinions on these issues: time for leisure and time for homework. For the purposes of this research the researcher has to advocate a baseline for the time spent on these activities. She feels that a child between the ages of 6 years and 18 years inclusive should have a minimum of 2 hours

leisure time and with regard to homework. The researcher feels that the minimum homework time for primary school children, who get homework, should be 1 hour and for senior children should be 2 hours. If one were to calculate the time taken for sleep, school, homework and then the 4 hours for caring, only three and a half hours would be left to get dressed twice, bath, eat three meals travel to and from school and play.

2.8.5 INAPPROPRIATE CARING IN TERMS OF WEIGHT

Fallon (1990), the Equal Opportunities Commission (1980) and the Co-ordinator of the Associations Care Attendant Scheme all agree that continuous lifting of a physcially disabled person can lead to serious back problems.

Cameron and Skofronick (1978) have already demonstrated the impact weight and incorrect lifting has on a person. The researcher has discussed this issue with experts who regularly lift physically disabled persons and they agree that a person can pick up half their weight with ease. If picking up more than half their weight

then two persons will be required to do the lifting or an expert.

2.8.6 INAPPROPRIATE CARING IN TERMS OF AGE

The researcher deduces from the various sources of literature that it would seem as if, age is relative and that it does not matter if you are 6 or 18 years old. But it does matter, is it appropriate in our day and age to expect an eight year old to cook food, do all the budgeting and all the housework. The researcher has already referred to several personal, initimate care activities which is considered to be inappropriate (cf. 2.8.3 : 34). It also has age implications. Girls in the age group, 16 to 18 years who have been exposed to menstruation for several years could therefore cope with this type of caring much better than girls in the 8 to 10 year age category who have not as yet started menstruating. The researcher is of the opinion that total or primary care could not be given by a young carer under the age of 18 years.

The researcher will address the objectives, scope and limitations of the research in the following chapter.

CHAPTER THREE

3. THE OBJECTIVES, SCOPE AND LIMITATIONS OF THE RESEARCH

3.1 THE OBJECTIVES OF THE RESEARCH

The objectives are:

3.1.1 to establish the types of caring activities young carers are involved in;

3.1.2 to assess appropriateness versus inappropriateness in terms of type of activity and time spent;

3.1.3 to assess the extent of inappropriate caring in terms of the age of the carer and his/her weight;

3.1.4 to make recommendations to the social service organisations to ease the plight of young carers;

3.1.5 to stimulate more extensive research into this subject.

3.2 THE SCOPE OF THE RESEARCH

3.2.1 CASES: The cases were taken from the CURRENT caseloads of the Association for the Physically

Disabled (Western Cape) and its branches. (cf. 3.2.2 :40)

3.2.2 GEOGRAPHICAL AREAS: The Association for the Physically Disabled (Western Cape) renders services in the following areas: Southern Suburbs, Cape Flats, Mitchells Plain, Strandfontein, Khayelitsha and the Boland areas which include: Somerset West to Villiersdorp, Malmesbury and Atlantis.

Branches : The Tygerberg Association for the Physically Disabled has as its geographical area the Northern Suburbs, Paarl Association for the Physically Disabled serves Paarl, Wellington, Stellenbosch, Saron and Wemmershoek. Worcester Association for the Physically Disabled serves Worcester, Rawsonville, Ceres, Bree River, De Doorns, Robertson, Montagu, Tulbagh and Wolseley. West Coast Association for the Physically Disabled renders services in Vredenburg, Velddrif, Saldanha and Langebaan.

The branches : which have been excluded from this

research are: additional local branches (cf. 3.1 :28), George Association for the Physically Disabled, Oudtshoorn Association for the Physically Disabled, Heidelberg Association for the Physically Disabled, Beaufort West Association for the Physically Disabled and the Namaqualand Association for the Physically Disabled. These branches were excluded because of the great distance involved: it would not have been cost effective to interview one or two clients who were approximately 500 kilometers out of Cape Town. A few of the local branches do not have social workers and therefore they were not included in the sample.

3.2.3 Population Group: All races

3.2.4 Sex: Both sexes

3.2.5 Age: 6 - 18 years of age. All children were included regardless of type of physical disability the client had.

3.2.6 Time: Interviews were conducted between July and

August 1991.

3.3 DEFINITION OF CONCEPTS

The researcher will briefly define the concepts as understood by the researcher for the purposes of this research.

3.3.1 Young Carers

The researcher defines young carers as follows: children between the ages of 6 and 18 years inclusive, who are involved in caring activities for dependent physically disabled persons without receiving payment.

3.3.2 Physically Disabled

A physically disabled person has a permanent impairment as a result of a locomotor disability.

3.3.3 Caring Activities

Caring activities involves the personal care of the physically disabled person as well as additional activities such as preparing meals, shopping and cleaning of the disabled person's

immediate environment.

3.3.4 Replacement activities

Replacement activities done by the young carers are activities which were or should be done by the physically disabled person, such as shopping and doing the family's washing.

3.3.5 Inappropriate Caring

Inappropriate caring involves activities which are not suitable in terms of type of activities, age appropriateness, necessitating more than 4 hours a day (28 hours per week and 112 hours per month) for a person who is physically disabled and weighs more than the young carer.

3.4 LIMITATIONS OF THE RESEARCH

3.4.1 The Population: The researcher stresses that this research project is limited because it only takes into account the current cases of the Association for the Physically Disabled (Western Cape) and only four of its nine rural branches, and two of its seven additional local branches.

3.4.2 Unidentified Young Carers: On a broader level, there are young carers who are known to other social service delivery organisations and a larger totally hidden unidentified number in the community which were also excluded.

3.4.3 Paucity of local literature : The researcher was able to find only one local research document which paid a limited amount of attention to adult carers. There was no local literature available on young carers.

3.4.4 Attitude of Respondents: The researcher had to be aware of the fact that this research could have been perceived by the clients as being negative and the children could have been warned to underplay their part in the caring activities, in order to counteract this, the researcher took the social worker concerned with her because this person was already known to the family.

The next chapter will outline the research design and methodology.

CHAPTER FOUR

4. RESEARCH DESIGN AND METHODOLOGY

This chapter addresses the research design and methodology used for this research.

4.1 THE DESIGN

This research falls in the province of exploratory research as outlined by Arkava and Lane (1983:96):

> Exploratory research helps practitioners determine more precisely the nature and form of a problem, so they then may formulate and test more specific research questions.

Selltiz and Otiz (1971) assert that the purpose of this type of research is to gain familiarity with a phenomenon or to achieve new insights into it.

The researcher is of the opinion that young carers are a new area of interest in South Africa. (cf. 2.8.1 : 31) The researcher has assumptions about the role of children in the homes of the physically disabled which will now be tested. It is also exploratory because no specific research has been

conducted locally on young carers.

4.2 THE HYPOTHESIS

Collins (in Meyer, 1986:3) points out that the main objective of exploratory research is "to refine concepts and hypothesis for further research." The researcher felt that at this point, she was unable to formulate a hypothesis. There were so many questions about the extent of caring being done by young carers that clarity was needed before more specific questions could be asked.

4.3 THE UNIVERSE

The universe was selected from the current caseload of the Association for the Physically Disabled (Western Cape) and its branches: Tygerberg, Paarl, Worcester and the West Coast (cf. 3.2.2 : 40). The researcher had requested that the social workers scrutinize their current caseloads to look for children between the ages of six years and eighteen years who reside in the homes of a disabled client. Two hundred and thirty one cases of physically disabled clients were identified by the social workers and submitted to the researcher. Four hundred and seventy children between the

ages of six years and eighteen years inclusive were identified in these two hundred and thirty-one cases, these children formed the universe.

The Association for the Physically Disabled (Western Cape) and its branches see clients with a variety of physical disabilities. The researcher has identified the disabilities which the disabled persons had who were represented as cases for the sample. (cf. Appendix 2 : 135)

4.4 THE SAMPLE

The sampling technique used was probability sampling; specifically, random sampling. Each social worker submitted a list with the following detail:

File no	Name of client	Diagnosis	Address	No. of ch. 6yrs-18yrs

Sixteen lists were submitted. To each list was assigned the first initial of the social worker's name and a numerical number for each item on the list. Forty-six cases were randomly selected by using an interval of three, which gave the researcher a sample of seventy-two respondents. At the time of the interviews only forty two cases were used as two cases had moved and the children of

two other cases were attending boarding schools. As a result of this, seven children represented in these cases were then excluded and therefore only 65 children were then interviewed.

4.5 RESEARCH TOOLS

4.5.1 Literature Review

Although the literature search yielded only a small amount of literature (which was primarily of British and Amercian origin) this nevertheless gave the researcher some insight into the field of study and provided some of the required information. Literature pertaining to the South African context was limited.

4.5.2 Interview Schedule

Several factors influenced the development of the interview schedule. It had to be designed (in such a way) that either a six year old or an eighteen year old could understand it. The questions were designed to cover the following areas: identifying particulars of the young carer, the disabled person, caring activities,replacement

activities and general. The interview schedule contained only 18 items but this proved to be satisfactory to explore the topic being researched.

4.5.3 Administration of the Interview Schedule

To test the effectiveness of the interview schedule, a pilot study was conducted. The pilot study was conducted with four cases which had been closed at the time the researcher requested the names for this research. During the pilot study ambiguous questions were identified and removed. The interview schedule was also reconstructed by adding the hours spent columns (cf. Appendix 4 : 143) which simiplified the questions on the caring activities and the replacement activities making it more manageable for the researcher.

The researcher personally conducted the interviews. The social worker in each instance accompanied the researcher to the homes of the respondents. The researcher was aware of the sensitive nature of the research and to gain

access to the children, thought it would be better to go with a person they already knew. The social workers in turn used this opportunity to conduct a counselling session with the disabled person.

The respondents were told that in the past the Association's services had been focussed on the disabled person. Now, they were looking further afield to the families, particularly the children to see if there was any kind of service the children needed. Hence, the research was designed to ask the children questions in an attempt to make recommendations.

The researcher introduced herself to the respondents and assured the respondents that she would only take a half an hour of their time. She also assured the respondents that the questions were not difficult. The researcher also ascertained which language would be convenient for the child and conducted the interview in the requested English or Afrikaans medium. This introduction relaxed the respondents sufficiently for the researcher to then ask the relevant

questions. The researcher was aware of interviewer bias but felt that the use of field workers would perhaps complicate the situation by introducing other forms of biases.

4.5.4 A Scale

The researcher used a scale to weigh the respondents. The same scale was used for all the interviews to ensure validity. It was a kilogram scale, ranging from 0 to 120 kilograms. The scale is also considered to be a valid measurement tool because it eliminated any possible errors which could have arisen if the weight was estimated.

The following chapter will deal with the analysis of the data gathered through the use of the interview schedule and the scale.

CHAPTER FIVE

5. DATA ANALYSES AND FINDINGS

This chapter reflects the data gathered by means of the interview schedule and the scale, (cf. 4.5.2 :48, 4.5.4:51). The researcher will evaluate the data and the findings will be presented in the form of tables, graphs, histograms, pie charts and a short discussion.

The contents of each section of the interview schedule will be evaluated and analyzed individually and if appropriate, in combination with other sections.

To obviate confusion when reading the results, the following may be useful:

i. The children in the study are referred to as young carers.

ii. Young carers are the respondents.

iii. Only where specified will the disabled persons be used in the presentation of data.

5.1 IDENTIFYING PARTICULARS OF THE YOUNG CARERS

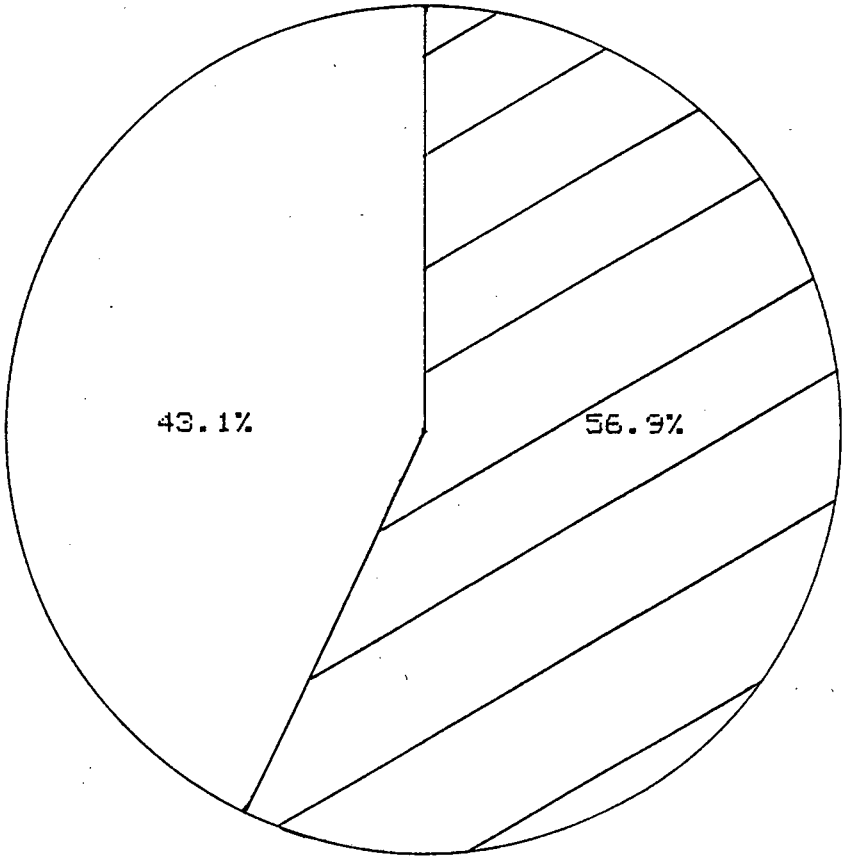
This section will contain a summary and a short discussion of the profile findings of the respondents.

5.1.1 TABLE: AGES OF RESPONDENTS

AGE	NO. OF RESPONDENTS	%
6	4	6.2%
7	4	6.2%
8	5	7.7%
9	4	6.2%
10	8	12.3%
11	2	3.0%
12	5	7.7%
13	6	9.2%
14	10	15.3%
15	4	6.2%
16	4	6.2%
17	3	4.6%
18	6	9.2%
	N = 65	100

The sample showed a fair representation of the age categories and there were respondents in each category. The highest number of respondents (10) appeared in the 14 year age category. The lowest number of respondents (3) were in the 17 year age category.

5.1.2 PIE CHART: SEX OF RESPONDENTS



KEY

MALE =

FEMALE =

There were 28 (43.1%) males and 37 (56.9%) females in the sample.

5.1.3 TABLE: RESPONDENTS ATTENDING SCHOOL

SCHOLARS	NO. OF RESPONDENTS	%
YES	60	92.4%
NO	5	7.6%
	N = 65	100%

60 (92.3%) of the respondents were scholars and 5 (7.6%) respondents were not. 2 of the 5 respondents who were not scholars had just turned 6 years old and would only start attending school in 1992. The researcher had asked for school-going children but in these instances the social workers had just used the age factor. 3 of the 5 respondents reported that they were no longer attending school because they had decided to help with the caring of the disabled person as no one was at home to do the caring. The youngest respondent who left school to do the caring was 15 years old. Here again the social workers were under the impression that these children were still attending school.

5.1.4 TABLE: SCHOOL STANDARDS OF THE RESPONDENTS

STANDARD	NO OF RESPONDENTS	%
SUB-A	2	3.3%
SUB-B	8	13.3%
1	5	8.3%
2	6	10.0%
3	5	8.3%
4	6	10.0%
5	8	13.3%
6	6	10.0%
7	7	11.7%
8	4	6.7%
9	2	3.3%
10	1	1.7%
	N = 60	100

The highest concentration of respondents (8) out of the 60 respondents who were scholars were in the standard 5 category. This table indicates that 20 (33.4%) respondents were in senior secondary school while 40 (66.6%) respondents were in primary school. The age categories indicated that

33 (55.0%) respondents were of senior secondary school age. In this research the objective was not to assess why, if any, causal factors related to the caring had an impact on the young carer's education. This is an important question which could form the basis of further research.

5.2 IDENTIFYING PARTICULARS OF THE PHYSICALLY DISABLED PERSON

This section will consist of a short discussion on the profile of the physically disabled person.

5.2.1 TABLE: CARERS RELATIONSHIP TO THE PHYSICALLY DISABLED PERSON

DISABLED PERSON'S RELATIONSHIP TO THE YOUNG CARER	NO OF PHYSICALLY DISABLED PERSONS	%
MOTHER	30	46.5%
FATHER	20	30.7%
SISTER	1	1.5%
BROTHER	10	15.3%
COUSIN	3	4.6%
OTHER	1	1.5%
	N = 65	100

The class which had the most physically disabled persons (30) was that of mothers. There were no aunts, uncles and grandparents in the cases from which the sample was drawn. There was only one respondent (1.5%) in the 'other' class and this was a 10 year old girl who cared for a neighbour who had a TB Spine (cf Appendix 2 : 135)

5.2.2 TABLE: TYPE OF PHYSICAL DISABILITY

(cf 5.2.2 : 59)

Amputations and paraplegia represented the highest number of physically disabled persons (10 and 11 respectively) per category. In both cases the persons could be wheelchair-bound. Bilateral amputees and paraplegics are trained to achieve independence by maximizing their arms so making them less dependent on care. In one case of the sample, a 13 year old boy was providing total care for his father who lost both his arms in an explosion. The categories quadraplegia and multiple sclerosis had 6 persons in each category. In both cases this type of disability at its severest stage can cripple all four limbs (cf. Appendix 2 : 135) and require total care.

All the other types of physical disabilities will be defined later (cf. Appendix 2 : 135).

5.2.2 TABLE: TYPE OF PHYSICAL DISABILITY

TYPE	NO OF PHYSICALLY DISABLED PERSONS	%
AMPUTATIONS	10	15.4%
CEREBRAL PALSY	5	7.7%
CONGENITAL MALFORMATION	4	6.2%
GULLIAINE BARRE	3	4.6%
HEAD INJURY	3	4.6%
HEMIPLEGIA	1	1.5%
HUNTINGTON'S DISEASE	1	1.5%
MULTIPLE SCLEROSIS	6	9.2%
MUSCULAR DYSTROPHY	3	4.6%
OSTEOGENESIS IMPERFECTA	1	1.5%
PARAPLEGIA	11	16.9%
POLIOMYELITIS	3	4.6%
QUADRAPLEGIA	6	9.2%
SPASTIC DISPLEGIA	3	4.6%
SPINA BIFIDA	1	1.5%
TB SPINE	4	6.2%
	N = 65	100

5.2.3 TABLE: AGES OF THE PHYSICALLY DISABLED PERSONS

AGES	NO OF PHYSICALLY DISABLED PERSONS	%
1 - 10	7	10.8%
11 - 20	6	9.2%
21 - 30	4	6.2%
31 - 40	36	55.4%
41 - 50	11	16.9%
51 - 60	1	1.5%
	N = 65	100%

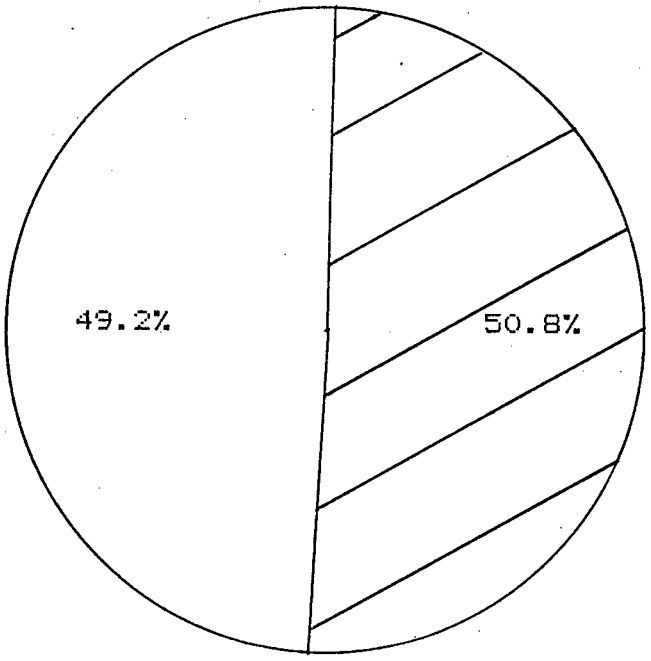
The majority of the physically disabled receiving care were adults. 52 (80%) persons were over the age of 20 years, 13 (20%) persons were 20 years and under. The greatest concentration of physically disabled persons (36) were in the 31-40 class.

Other than the weight, no further information with regard to the profile of the physically disabled person was ascertained.

5.3 INAPPROPRIATE TYPES OF CARING ACTIVITIES

This section forms one of the most important aspects of this research.

5.3.1 PIE CHART: THE NUMBER OF YOUNG CARERS INVOLVED IN INAPPROPRIATE TYPES OF CARING ACTIVITIES



KEY

NOT INVOLVED =

INVOLVED =

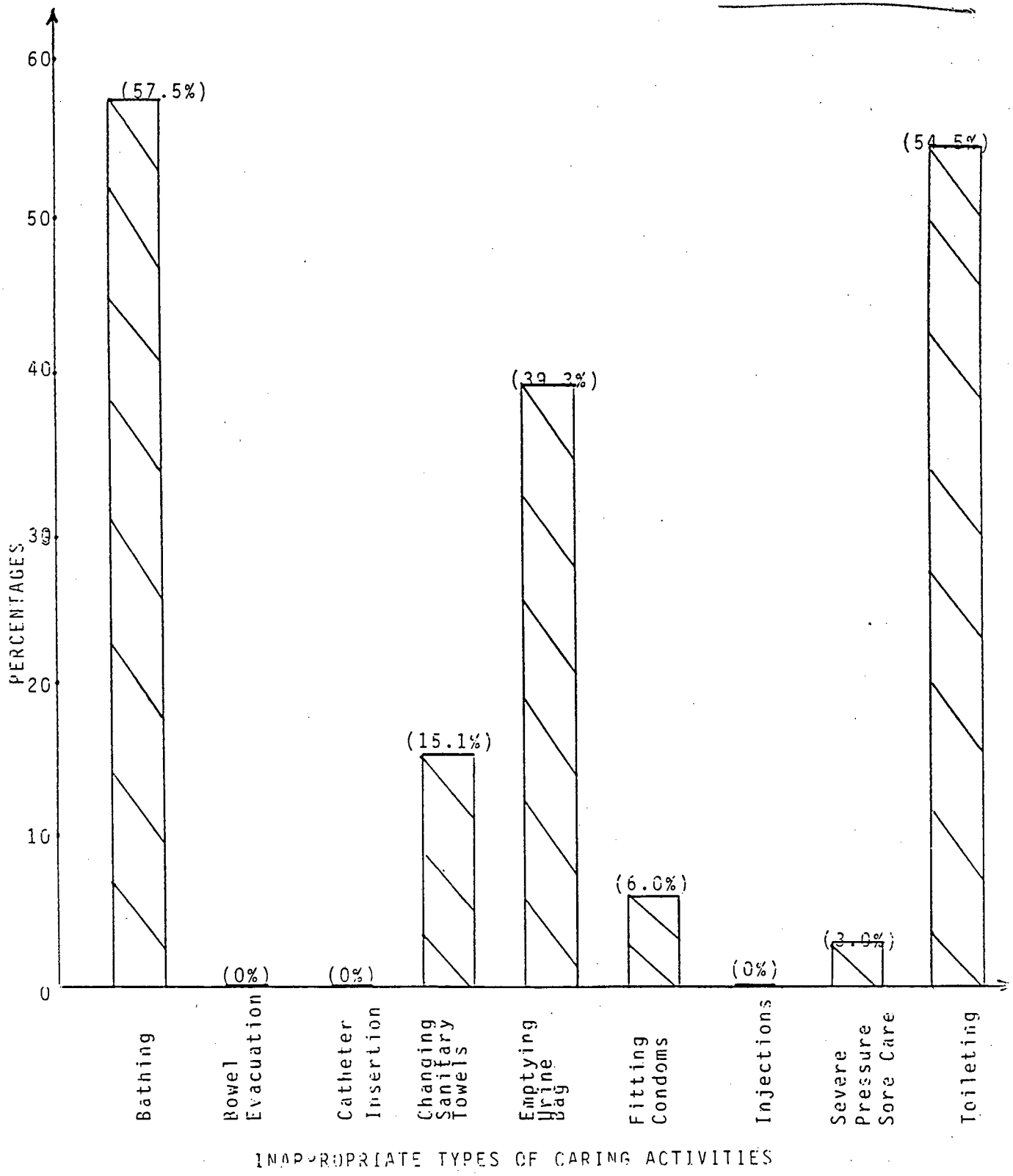
The interview schedule yielded the following findings. Only 33 (50.8%) respondents were involved in inappropriate types of caring activities. The remaining 32 (49.2%) respondents' schedules were therefore set aside and all further data analysis was conducted with the 50.8%

5.3.2 TABLE: SEX OF YOUNG CARERS INVOLVED IN INAPPROPRIATE TYPES OF CARING ACTIVITIES

SEX	NO OF RESPONDENTS	%
MALE	18	54.5%
FEMALE	15	45.5%
	N = 33	100

This table reflects that there were more male (18) young carers than female (15) young carers involved in inappropriate types of caring activities. This is a significant factor when considering that there are more mothers (46.5%) than fathers (30.7%) who the young carers were caring for. Also some of these caring activities (cf.5.3.3 : 63) have initimate implications, for example, changing sanitary towels.

5.3.3 HISTOGRAM: INAPPROPRIATE TYPES OF CARING ACTIVITIES



The researcher had left additional space on the interview schedule for activities which the respondents felt should be on the list of caring activities (cf. Appendix 4 : 143). The respondents added several types of caring activities, the researcher considered the following to be additional inappropriate caring activities: emptying and cleaning a urine bag, fitting a condom for an incontinent person who does not use a catheter and cleaning and bandaging severe pressure sores.

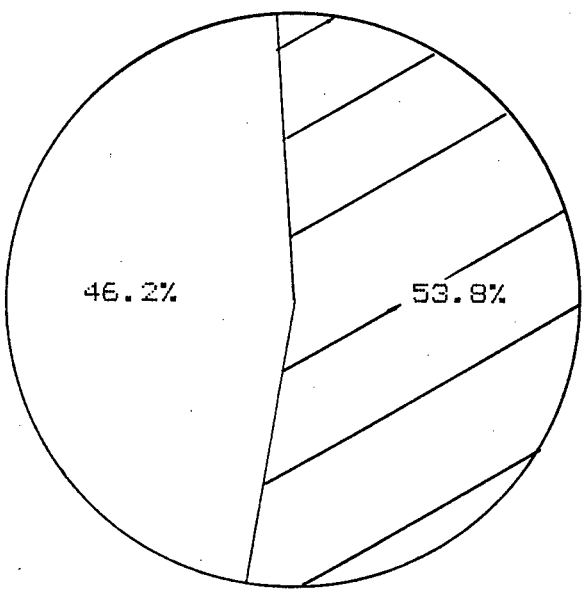
The respondents claimed not to be involved in the following types of caring activities: bowel evacuation; catheter insertion and injections. All wheelchair-bound persons need to have some form of bowel regime because they have no feeling in that area. In some cases it can be done through using laxatives and in other instances manual evacuation would be required. This is a sensitive issue and the respondents appeared to prefer to just leave it at assisting with toileting, than to be so specific despite the question being asked. The two inappropriate types of caring activities that had the highest frequency were bathing (57.5%) and toileting (54.5%). 7 (21.1%) respondents admitted to changing sanitary towels and fitting condoms. A 15 year old young carer described her worst type of caring activity as that of changing the bandages and cleaning an

enormous pressure sore which took an hour of her time. This section provided the researcher with the evidence that young carers are involved in inappropriate type of caring activities for the physically disabled.

5.4 INAPPROPRIATE CARING IN TERMS OF TIME

This section will analyze the time in terms of hours per day, week and month. The researcher has already set the baseline with regard caring that is inappropriate: exceeds 4 hours per day; 28 hours per week and 112 hours per month (cf. 3.3.2.2 : 35)

5.4.1 PIE CHART: NUMBER OF RESPONDENTS INVOLVED IN INAPPROPRIATE CARING IN TERMS OF TIME



KEY

TIME APPROPRIATE =
TIME INAPPROPRIATE =

This diagram indicates that 35 (53.8%) respondents were caring in excess of 28 hours per week. 30 (46.2%) respondents spent less than 28 hours per week caring.

5.4.2 GRAPH: NUMBER OF HOURS SPENT CARING PER DAY

(cf. 5.4.2 : 67)

This graph indicates that the highest frequency was at the 4 (29.2%) hour and over mark. 35 (53.8%) respondents were involved in caring that exceeded 4 hours. The lowest amount of time caring was 20 minutes (.33%) per day.

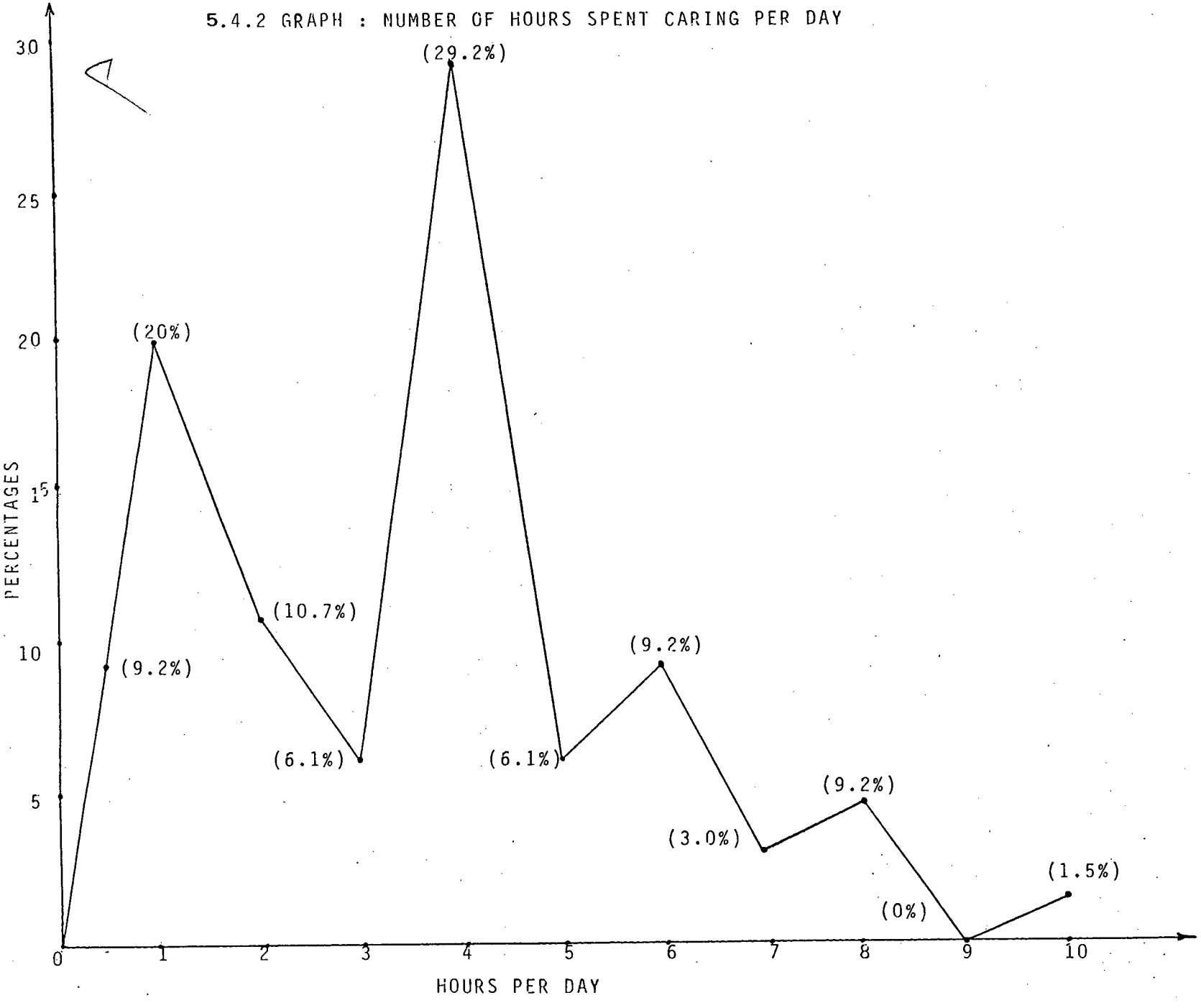
The most excessive caring per day was 10 hours and 45 minutes. This respondent is a 15 year old girl who is providing total care for her mother who has a TB Spine and is bedridden.

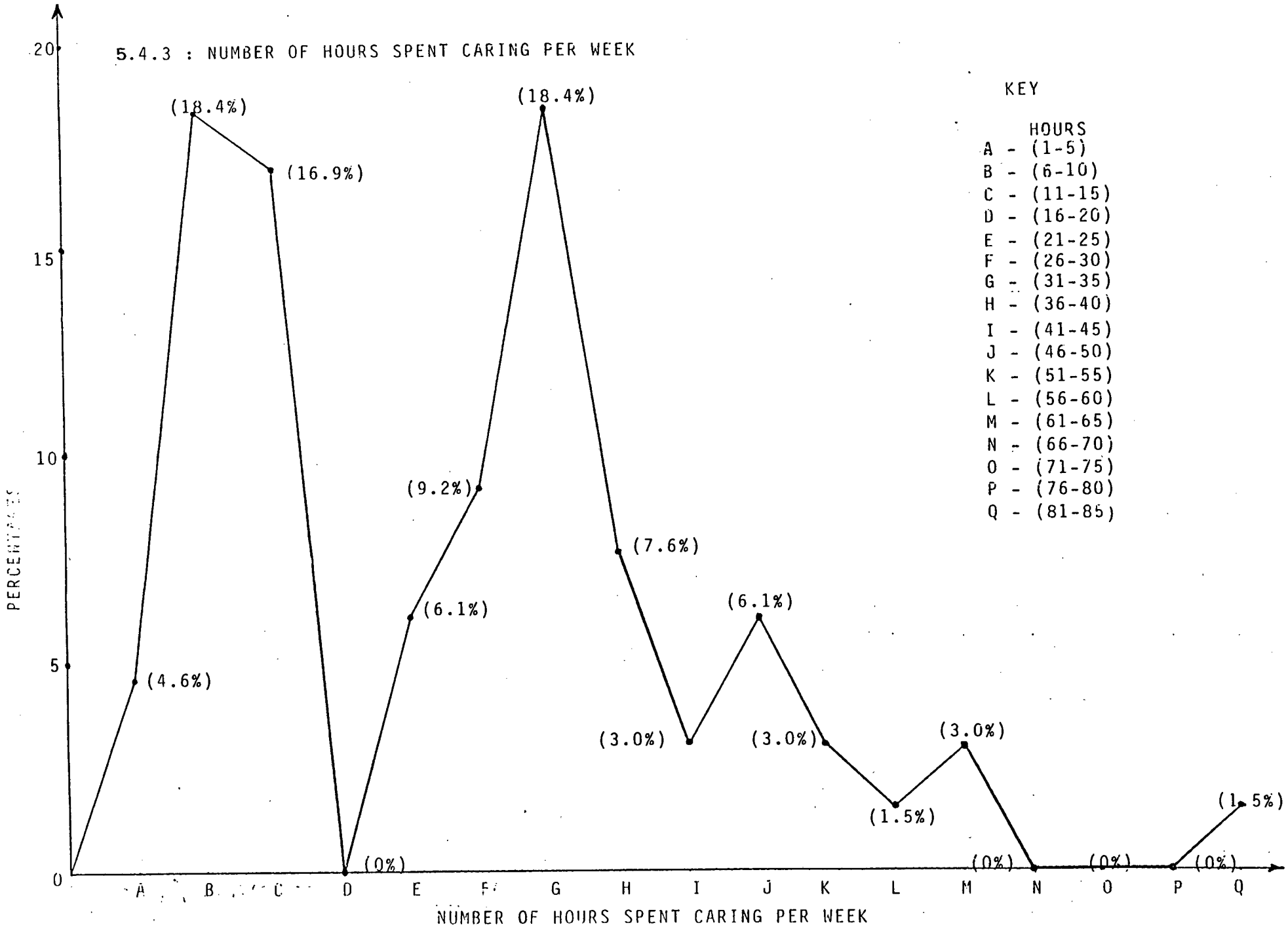
5.4.3 GRAPH: NUMBER OF HOURS SPENT CARING PER WEEK

(cf. 5.4.3 : 68)

The baseline for hours of caring per week is 28 hours. So hours in excess of 28 hours is seen as being inappropriate in terms of time. The highest frequency was 12 (18.4%) respondents on both sides of the baseline.
Despite this, the 35 (53.8%) respondents involved in

5.4.2 GRAPH : NUMBER OF HOURS SPENT CARING PER DAY




5.4.3 : NUMBER OF HOURS SPENT CARING PER WEEK
KEY
HOURS
A - (1-5)
B - (6-10)
C - (11-15)
D - (16-20)
E - (21-25)
F - (26-30)
G - (31-35)
H - (36-40)
I - (41-45)
J - (46-50)
K - (51-55)
L - (56-60)
M - (61-65)
N - (66-70)
O - (71-75)
P - (76-80)
Q - (81-85)
PERCENTAGES
0
5
10
15
20
(4.6%)
(18.4%)
(16.9%)
(0%)
(6.1%)
(9.2%)
(18.4%)
(7.6%)
(3.0%)
(6.1%)
(3.0%)
(1.5%)
(3.0%)
(0%)
(0%)
(0%)
(1.5%)
A
B
C
D
E
F
G
H
I
J
K
L
M
N
O
P
Q
NUMBER OF HOURS SPENT CARING PER WEEK

inappropriate caring in terms of time were still in the majority.

5.4.4 GRAPH: NUMBER OF HOURS SPENT CARING PER MONTH

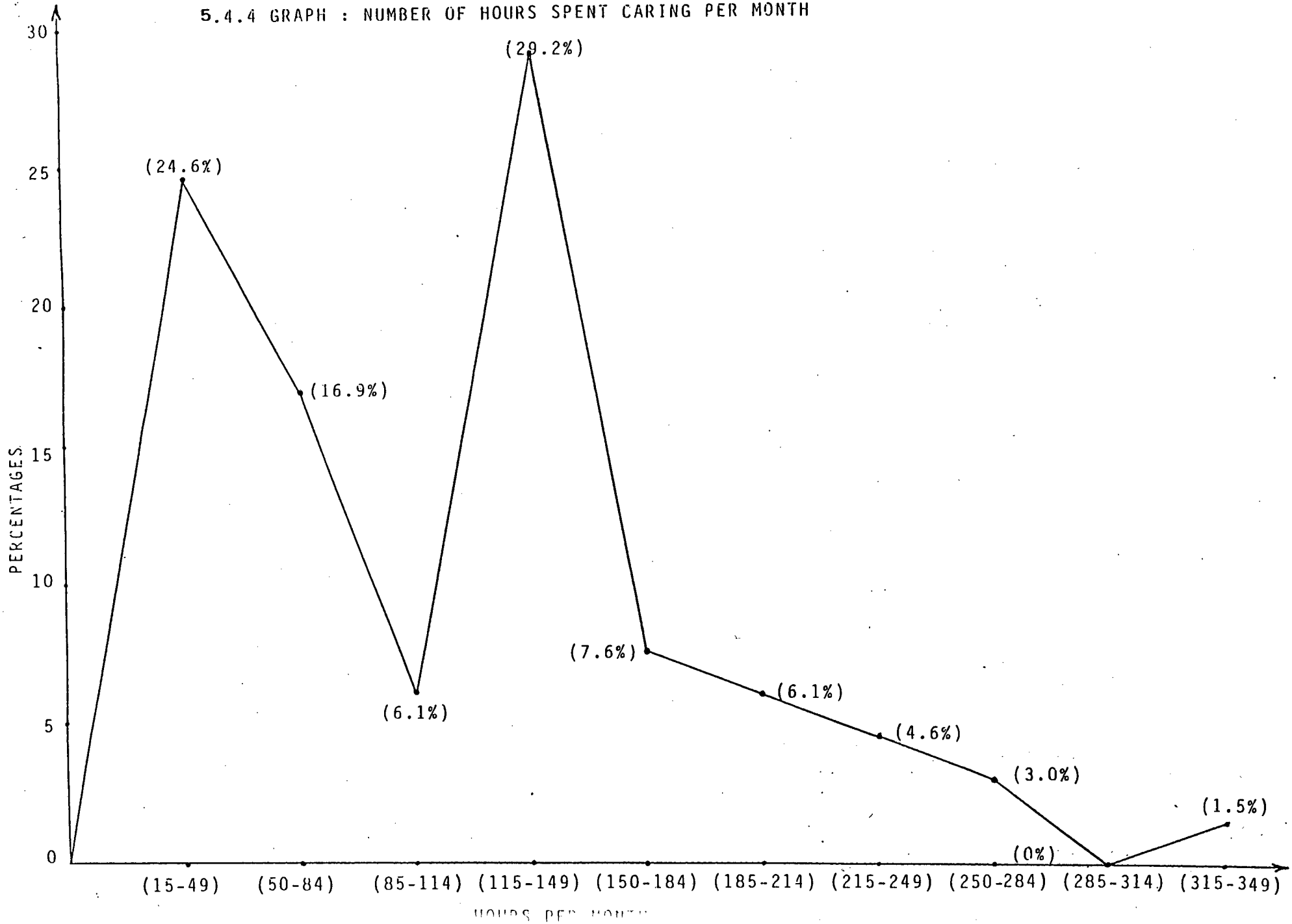
(cf. 5.4.4 : 70)

The young carers who spent more than 112 hours per month caring were caring inappropriately in terms of time. The graph on the monthly hours spent indicates that the category 115-149 hours (29.2%) to have the most respondents (19). The average amount of hours of caring in this category was 132 hours per young carer. 36 (55.3%) young carers were indicated as caring inappropriately in terms of time.
The international literature recorded that the carers who needed help were caring between 4 to 6 hours per day (28 to 42 per week, 112 to 168 hours per month)

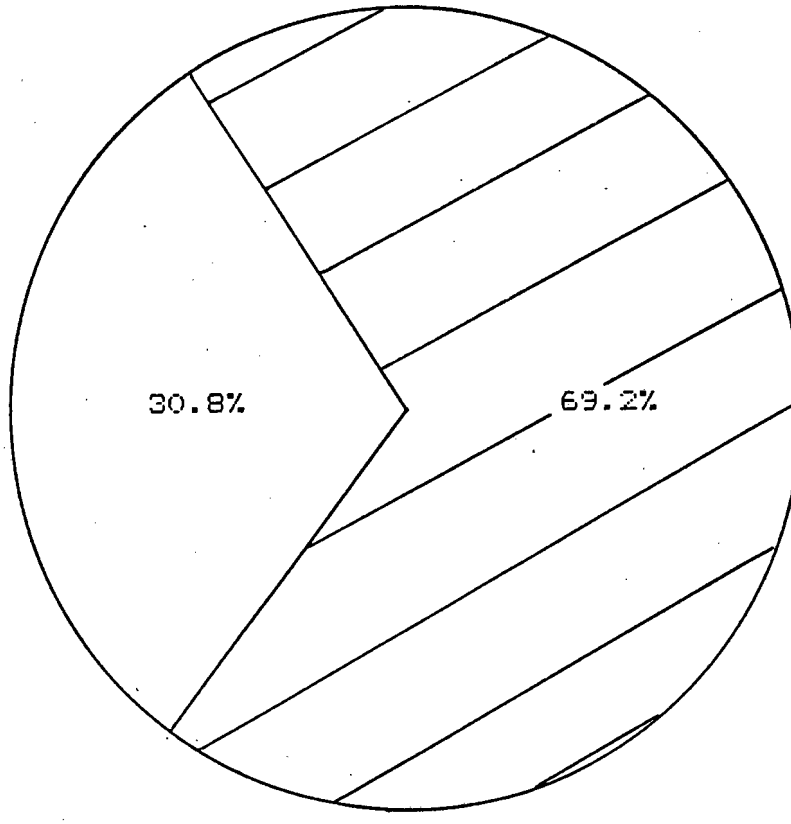
5.5 INAPPROPRIATE CARING IN TERMS OF WEIGHT

This section will look at the respondent's weight as opposed to the weight of the physically disabled persons in an attempt to establish if inappropriate caring in terms of weight was taking place.

5.4.4 GRAPH : NUMBER OF HOURS SPENT CARING PER MONTH



5.5.1 PIE CHART: THE NUMBER OF RESPONDENTS INVOLVED IN INAPPROPRIATE CARING IN TERMS OF WEIGHT



KEY

NOT INVOLVED =

INVOLVED =

The pie chart presents the following findings: 45 (69.2%) respondents were involved in inappropriate caring in terms of weight, while 20 (30.8%) respondents were not involved in weight-related activities.

5.5.2 GRAPH: INDICATING THE WEIGHT DIFFERENCES BETWEEN THE YOUNG CARERS AND THE PHYSICALLY DISABLED PERSON

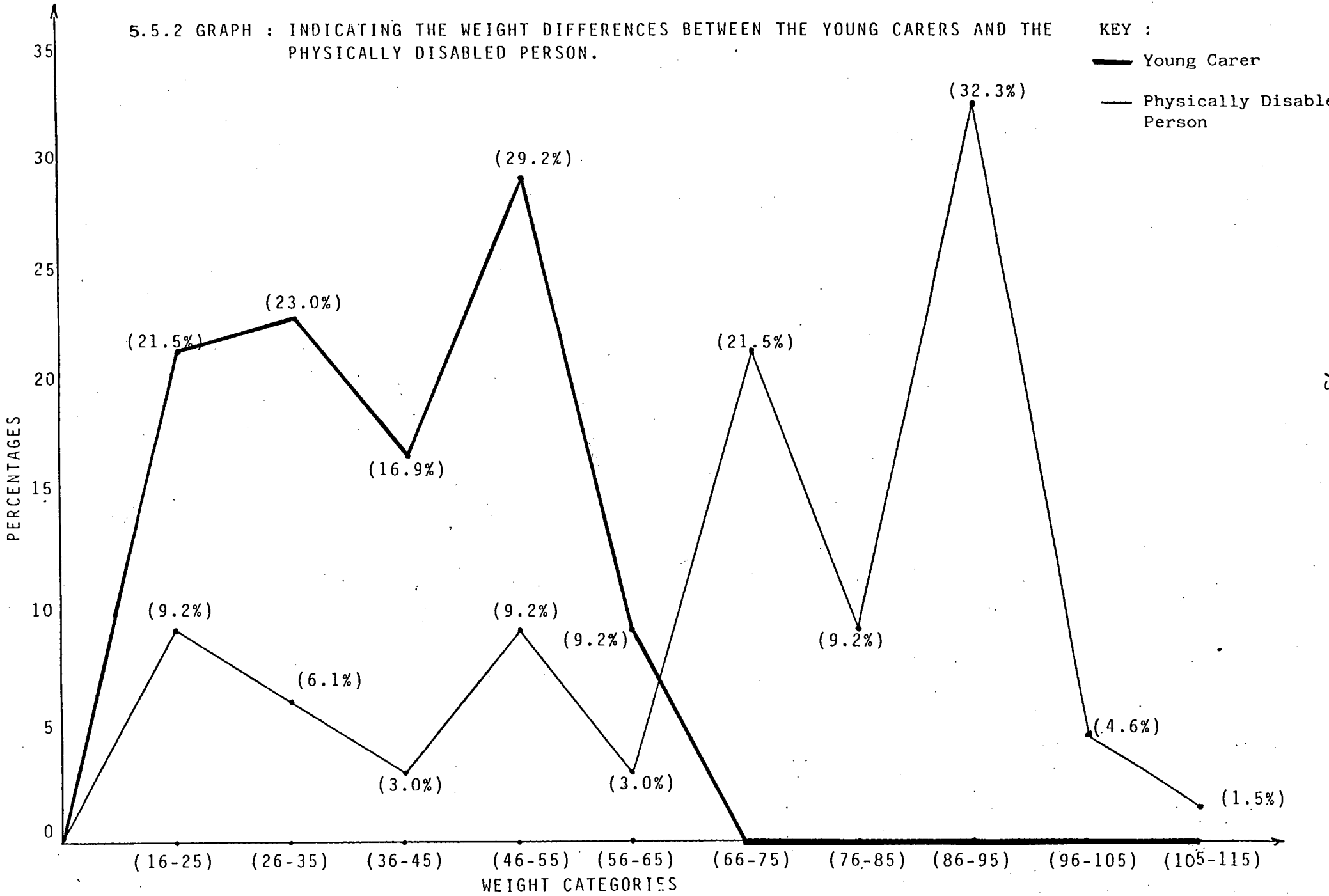
(cf. 5.5.2 : 73)

The graph is a combination of the weights of the young carers and the physically disabled persons. It highlights the significant discrepancies between the two groups. The highest percentage young carers (29.2%) were found in the 45-55 kilogram weight category. The highest percentage (32.3%) disabled persons were found in the 86-95 kilogram category. All the young carers weights did not exceed 65 kilograms. The majority of the physically disabled persons (45 respondents) weights were in excess of 65 kilogram.

The lowest frequencies occurred in the following caring activities: assisting with walking, 6 respondents and picking up the wheelchair, 3 respondents.

The inappropriate caring activities with regard to weight represented the highest number of respondents and the

5.5.2 GRAPH : INDICATING THE WEIGHT DIFFERENCES BETWEEN THE YOUNG CARERS AND THE PHYSICALLY DISABLED PERSON.



frequencies for the individual activities were also very high.

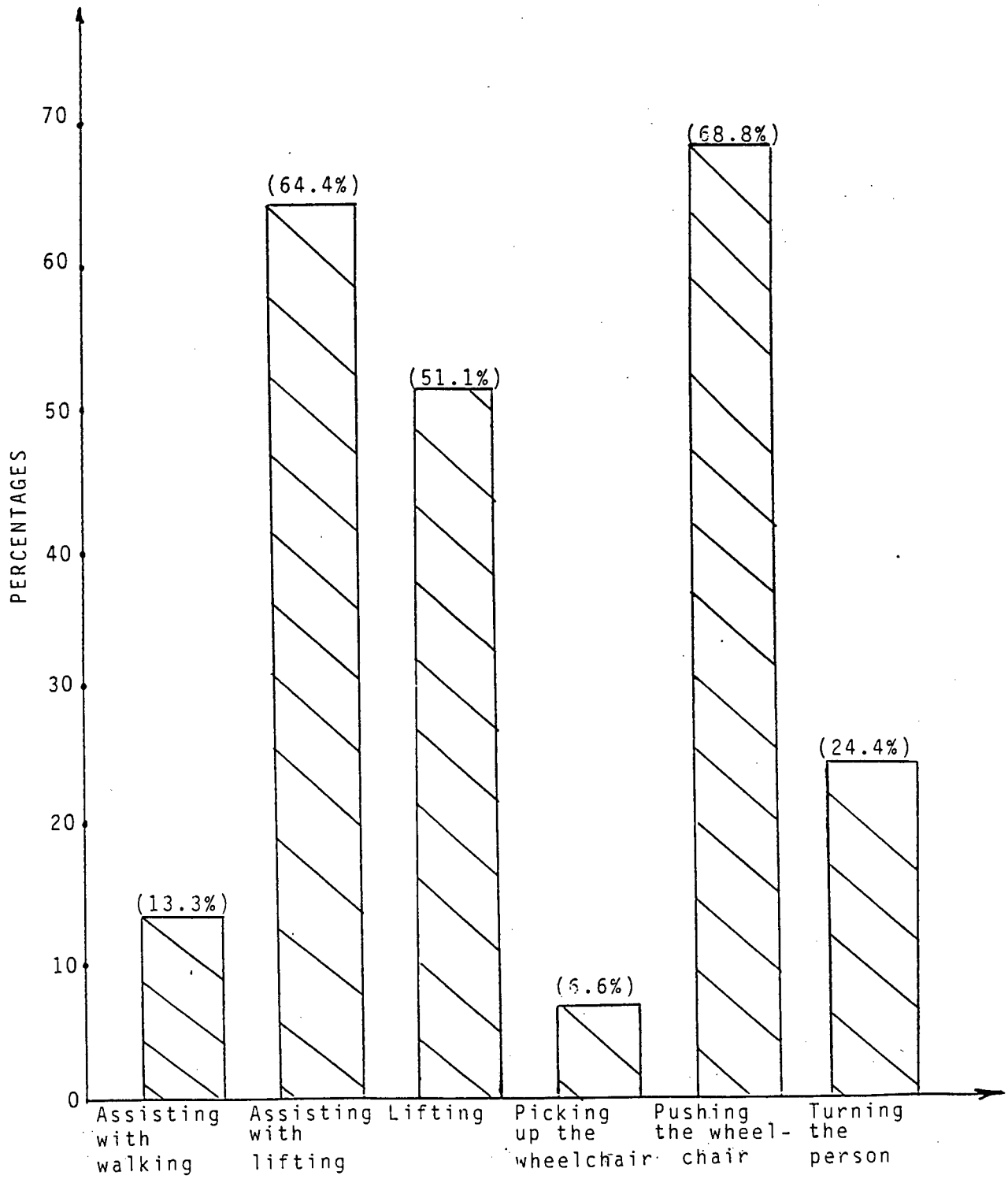
5.5.3 HISTOGRAM: INAPPROPRIATE CARING ACTIVITIES IN TERMS OF WEIGHT

(cf. 5.5.3 : 75)

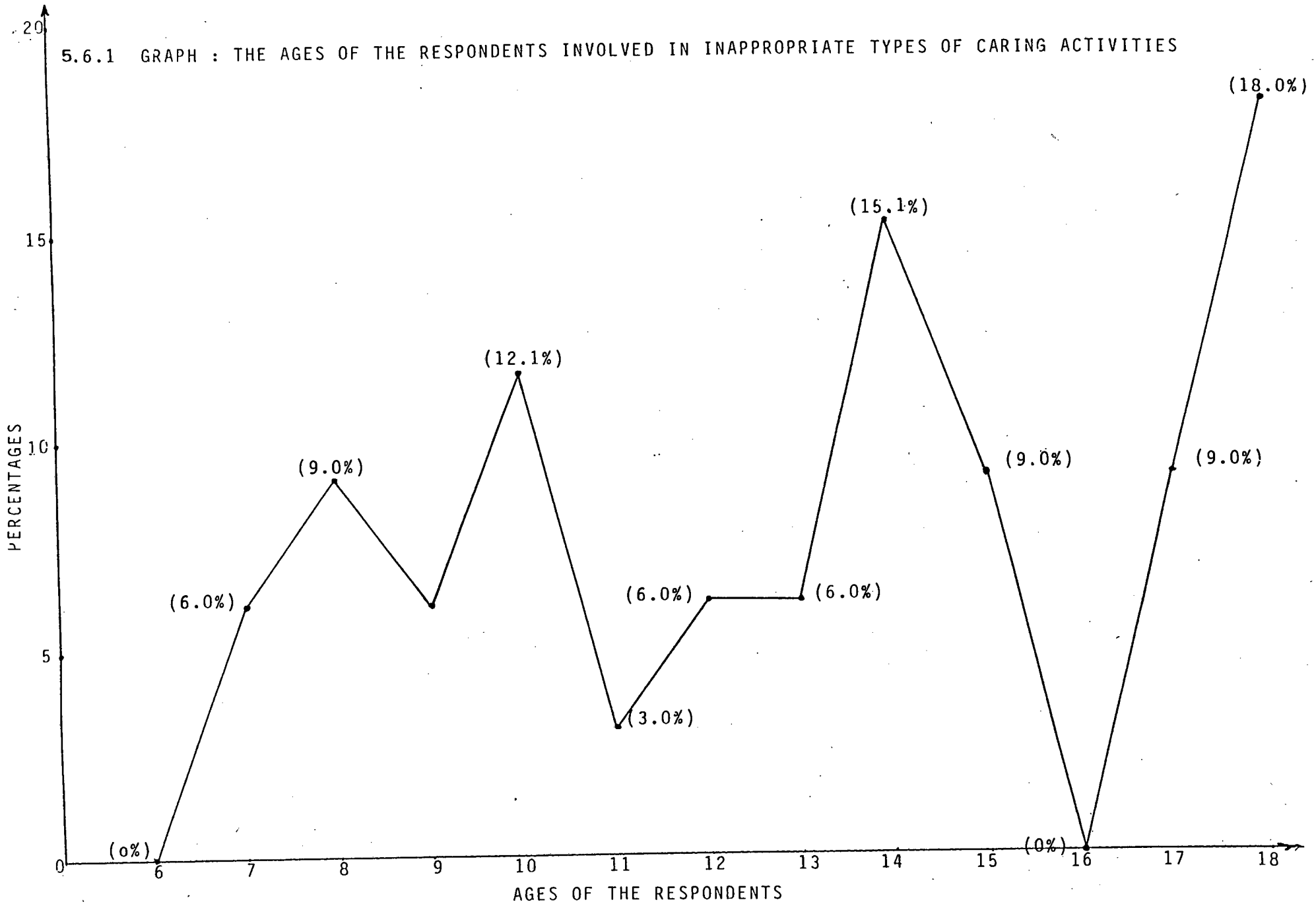
As already stated, 45 (69.2%) respondents were involved in inappropriate caring in terms of weight. These 45 respondents were asked if there were any additional caring activities they were involved in. The researcher considered one of the additional activities, picking up the wheelchair to be inappropriate in terms of weight. The caring activity which presented with the highest frequency (68.8%) was pushing the wheelchair.

The second largest group (64.4%) were involved in assisting someone else in lifting the physically disabled person. The third group - despite the enormous discrepancies in the weights - were in fact, the respondents (51.1%) who directly assist in the lifting of the person without any help. 11 (24.4%) respondents had to regularly turn the physically disabled person.

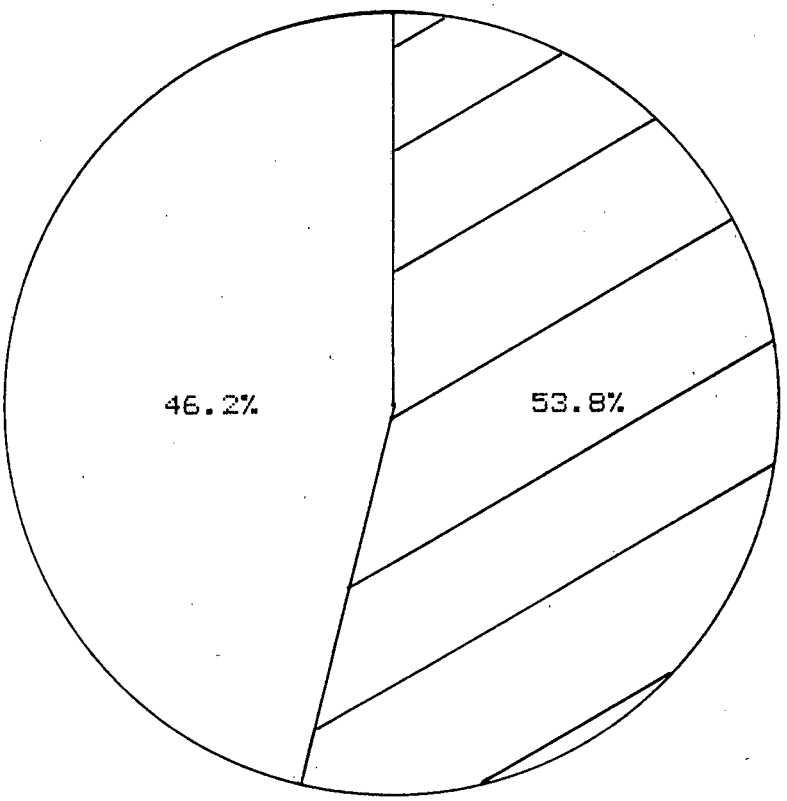
5.5.3 HISTOGRAM: INAPPROPRIATE CARING ACTIVITIES IN TERMS OF WEIGHT



5.6.1 GRAPH : THE AGES OF THE RESPONDENTS INVOLVED IN INAPPROPRIATE TYPES OF CARING ACTIVITIES

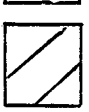


5.6.2 PIE CHART: NUMBER OF RESPONDENTS INVOLVED IN INAPPROPRIATE HOURS OF CARING WITH AN AGE COMPONENT



KEY

NOT INVOLVED =

INVOLVED = 

35 respondents in different age groups ranging from 7-18 years were involved in inappropriate caring in terms of time and age.

5.6.3 GRAPH: THE AGES OF THE RESPONDENTS WITH REGARD TO HOURS OF CARING PER WEEK

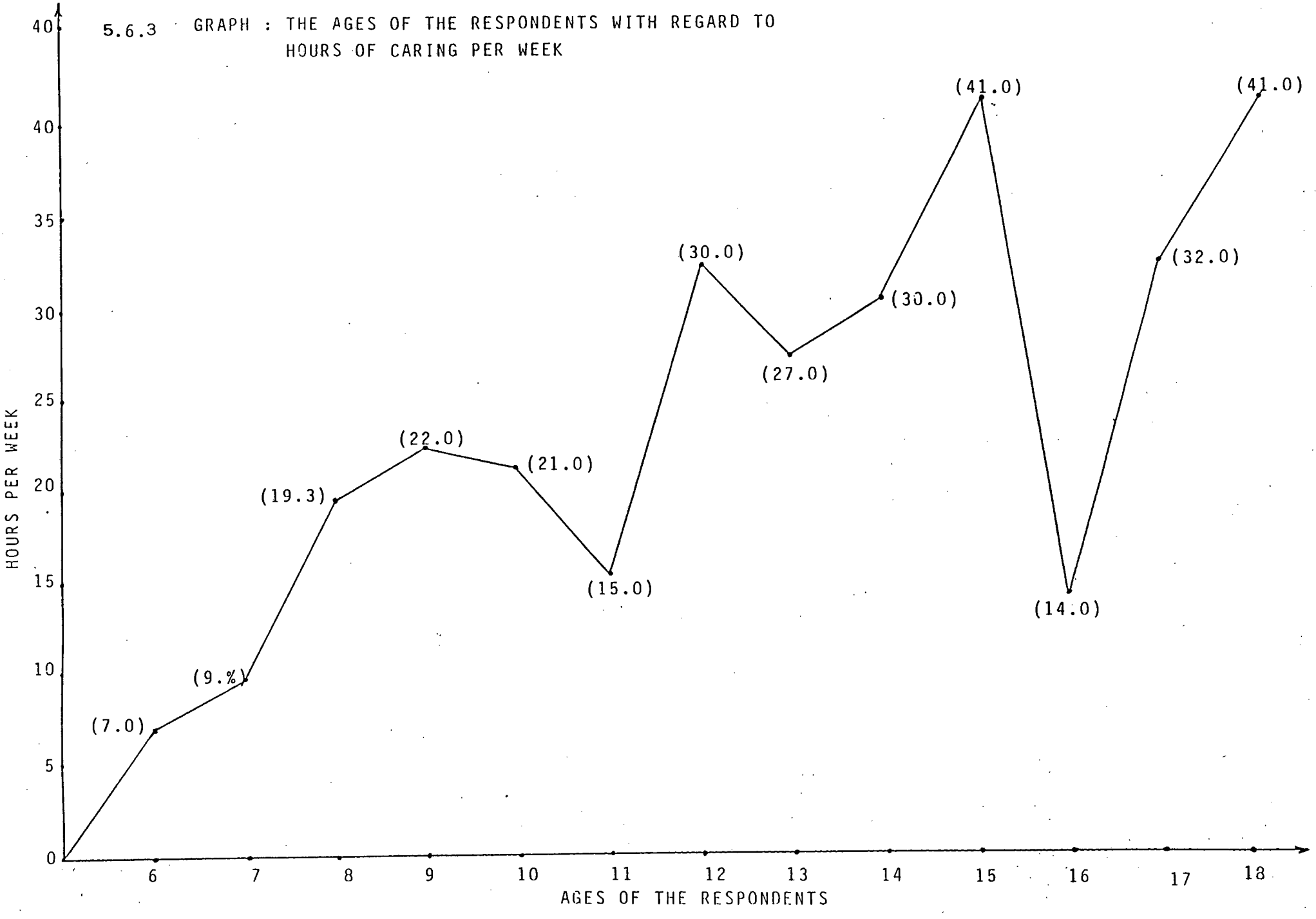
(cf. 5.6.3 : 80)

This graph shows that even a 6 year old spends 1 hour per day (7 hours per week) caring for a physically disabled person.

The following age categories all indicated more than 28 hours caring per week: 12 years, 13 years, 14 years, 15 years, 17 years and 18 years. The respondents in the age categories 15 years and 18 years spent 41 hours caring per person per week.

Below the baseline the respondents in the 9 years category spent 22 hours caring per week, which is not much less than 28 hours per week.

5.6.3 GRAPH : THE AGES OF THE RESPONDENTS WITH REGARD TO HOURS OF CARING PER WEEK



5.6.4 TABLE: AVERAGE HOURS OF CARING PER WEEK IN SPECIFIC AGE CATEGORIES

AGE	NO. OF RESPONDENTS	AVERAGE HOURS
7	1	39.0
8	1	29.58
9	2	33.24
10	5	38.11
11	-	-
12	4	38.5
13	4	35.9
14	5	44.18
15	4	50.6
16	1	40.0
17	3	32.22
18	5	46.6

This table reveals that the highest average hours of caring per week per age category was in the 15 year category. An average of 50.6 hours was being spent by a 15 year old on caring per week. This averages out to 7.2 hours per day.

The highest number of respondents (5) were found in the 10, 14 and 18 year old categories with averages of 38.11, 44.18 and 46.6 hours per week per person respectively.

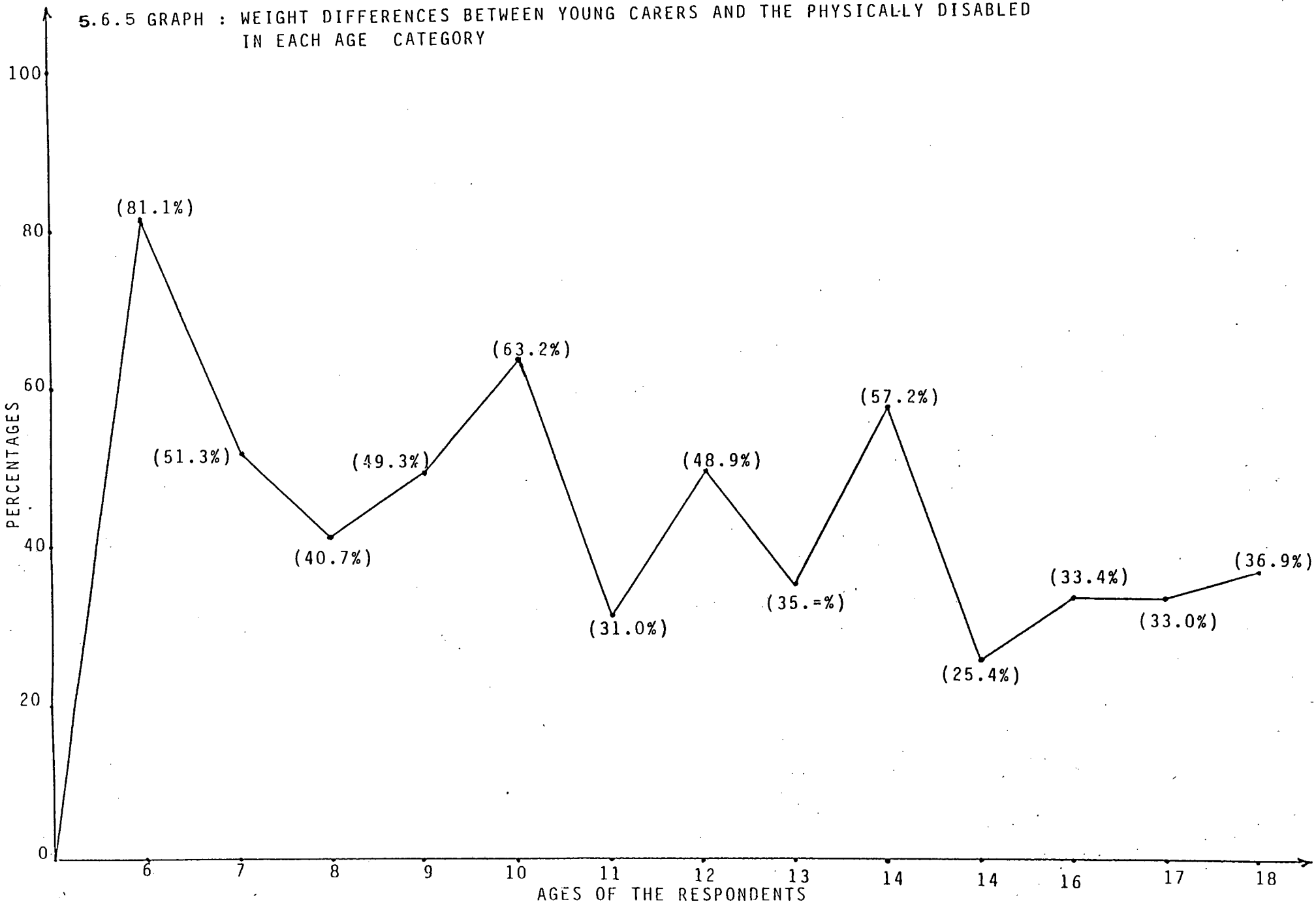
A fifteen year old would normally spend 7 hours at school, 2 hours on homework and if, as is indicated the young carer spends 7 hours on caring, then only 8 hours would be left for sleep. If this is indeed the picture the young carer would have had no time to eat, get dressed and travel to and from school and have leisure time.

5.6.5 GRAPH: WEIGHT DIFFERENCES BETWEEN YOUNG CARERS AND THE PHYSICALLY DISABLED IN EACH AGE CATEGORY

(cf. 5.6.5 : 83)

For this graph the average weights of the respondents and the average weights of the physically disabled persons were taken in each age category. This highlighted the weight difference between the two for each age category, for example, the young carer's weight average in the 6 year old category was 18 kilograms and the disabled person's was 95 kilograms so the weight difference was 77 kilograms (81.1%). A six year old related how she has to lift her father's legs up to put each foot on the step of the wheelchair. With the type of weight difference the researcher has just mentioned

5.6.5 GRAPH : WEIGHT DIFFERENCES BETWEEN YOUNG CARERS AND THE PHYSICALLY DISABLED IN EACH AGE CATEGORY



this type of caring is considered inappropriate. The youngest person who assisted with a lifting a the disabled person was 7 years old. The weight difference in this category was 33 kilograms which indicates the weight of the physically disabled person to be twice the weight of the young carer.

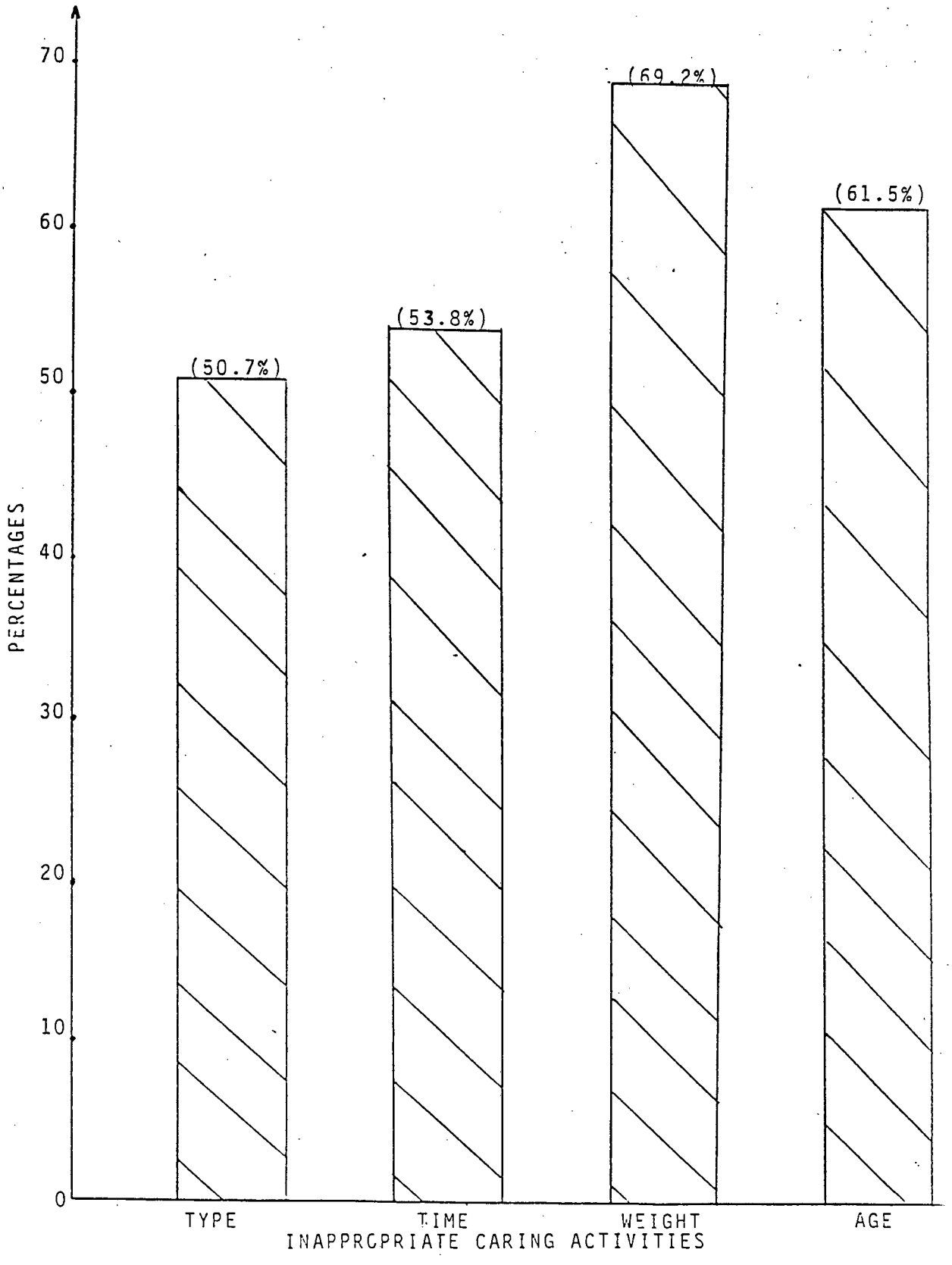
In Chapter 3 (cf. 2.8.5 : 37) the researcher asserted that the young carer would only be able to pick up half his weight. This is also relevant when assisting someone else to avoid incurring back injuries. The lowest weight difference occurred in the 15 year age category which was 16.3 kilograms (25.4%). 45 (69.2%) respondents were involved in inappropriate caring in terms of weight and age.

To end off this sub-section the researcher will show the percentages of the different types of inappropriate caring.

5.6.6 HISTOGRAM: THE PERCENTAGES OF THE INAPPROPRIATE CARING (cf. 5.6.6 : 85)

This diagram indicates that the most inappropriate caring was in terms of weight (69.2%). The category which showed the least number of respondents (50.7%) was that of inappropriate types of caring activities.

5.6.6 HISTOGRAM: THE PERCENTAGES OF INAPPROPRIATE CARING

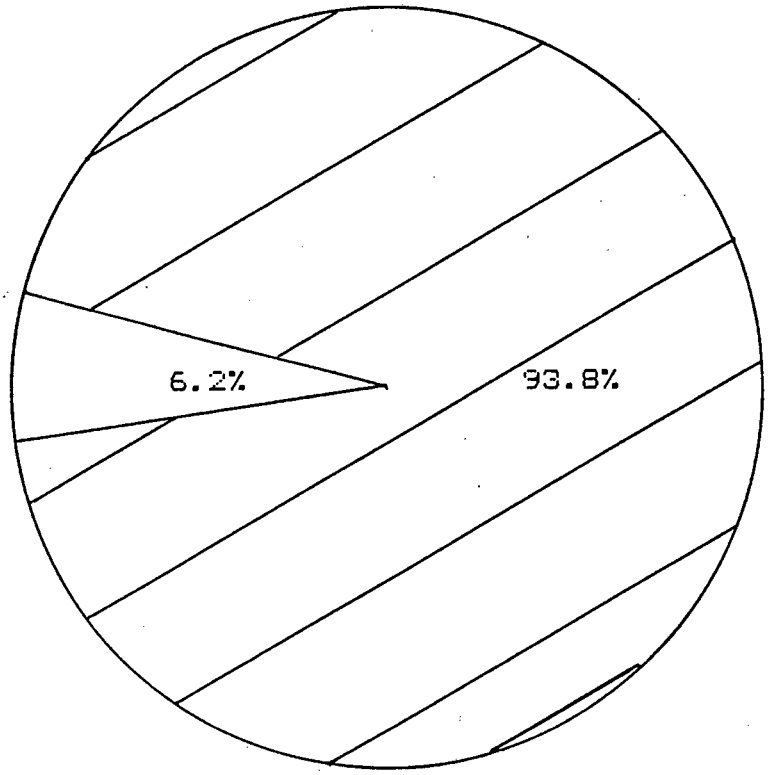


This histogram presents the researcher with a global picture of the evidence that young carers are involved in inappropriate caring activities. The concretized variables: type of caring activity, time, weight and age have been tested and have proven the extent and the nature of the inappropriateness of the care young carers render to the physically disabled person. The average of the various inappropriate caring activities indicate conclusively that 56.8% of the respondents (37) were involved in inappropriate caring.

5.7 REPLACEMENT ACTIVITIES

These activities refer to activities that the physically disabled person could have been doing before his/her disablement. It also refers to activities that would normally be done by the physically disabled person.
(cf. 3.3.4 : 43)

5.7.1 PIE CHART: NUMBER OF RESPONDENTS INVOLVED IN THE REPLACEMENT ACTIVITIES



KEY

NOT INVOLVED =
INVOLVED =

This diagram indicates that only 61 (93.8%) respondents were involved in replacement activities. Of the remaining 4 respondents there was a 6 and a 7 year old who were not involved in any replacement activity. The other two consisted of an 8 and a 12 year old girls who were not involved in replacement activities for their fathers but spent all their time caring. The 8 year old was involved in

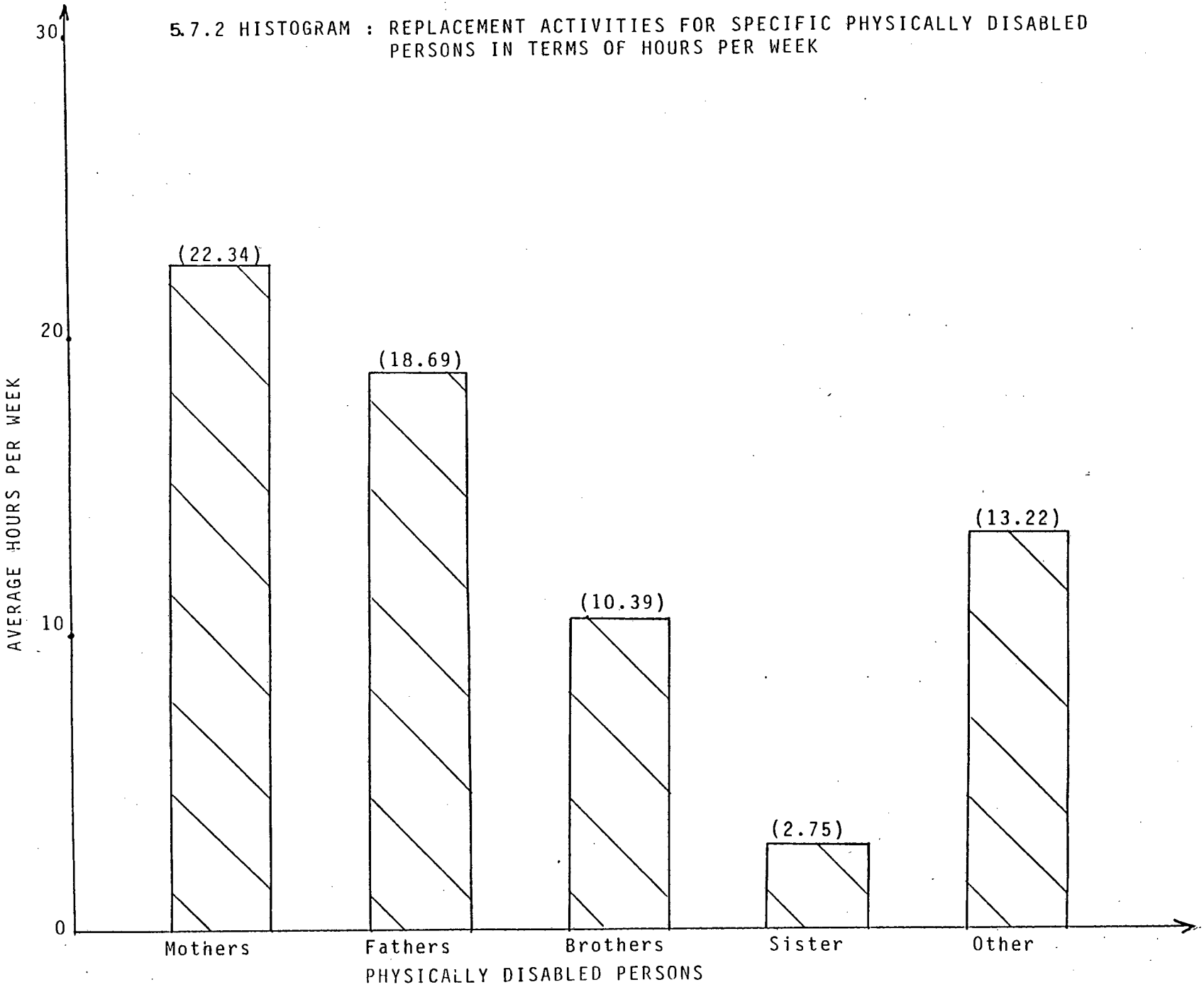
29.35 hours and the 12 year old was involved in 62.30 hours of caring per week, these both exceeded the 28 hour baseline, so therefore it is considered inappropriate in terms of time. The latter had the third highest amount of hours spent caring per week out of the whole sample.

5.7.2 HISTOGRAM: REPLACEMENT ACTIVITIES FOR SPECIFIC PHYSICALLY DISABLED PERSONS IN TERMS OF HOURS PER WEEK

(cf.5.7.2 : 89)

The histogram shows that 27 respondents were involved in doing replacement activities for mothers. It registered the most hours, 604.25 hours which averages to 22.34 hours per young carer per week, doing the following replacement activities: preparing a meal, and washing clothes to mention just two. 18 respondents were involved in replacement activities for fathers and these 18 resulted in 336.42 hours per week. The replacement activities per person on average was 18.69 hours per week. Brothers and sister replacement activities only involved 9 and 1 respondents respectively. The other, in this instance, refers to 5 respondents involved in replacement activities for 4 cousins and 1 neighbour.

5.7.2 HISTOGRAM : REPLACEMENT ACTIVITIES FOR SPECIFIC PHYSICALLY DISABLED PERSONS IN TERMS OF HOURS PER WEEK



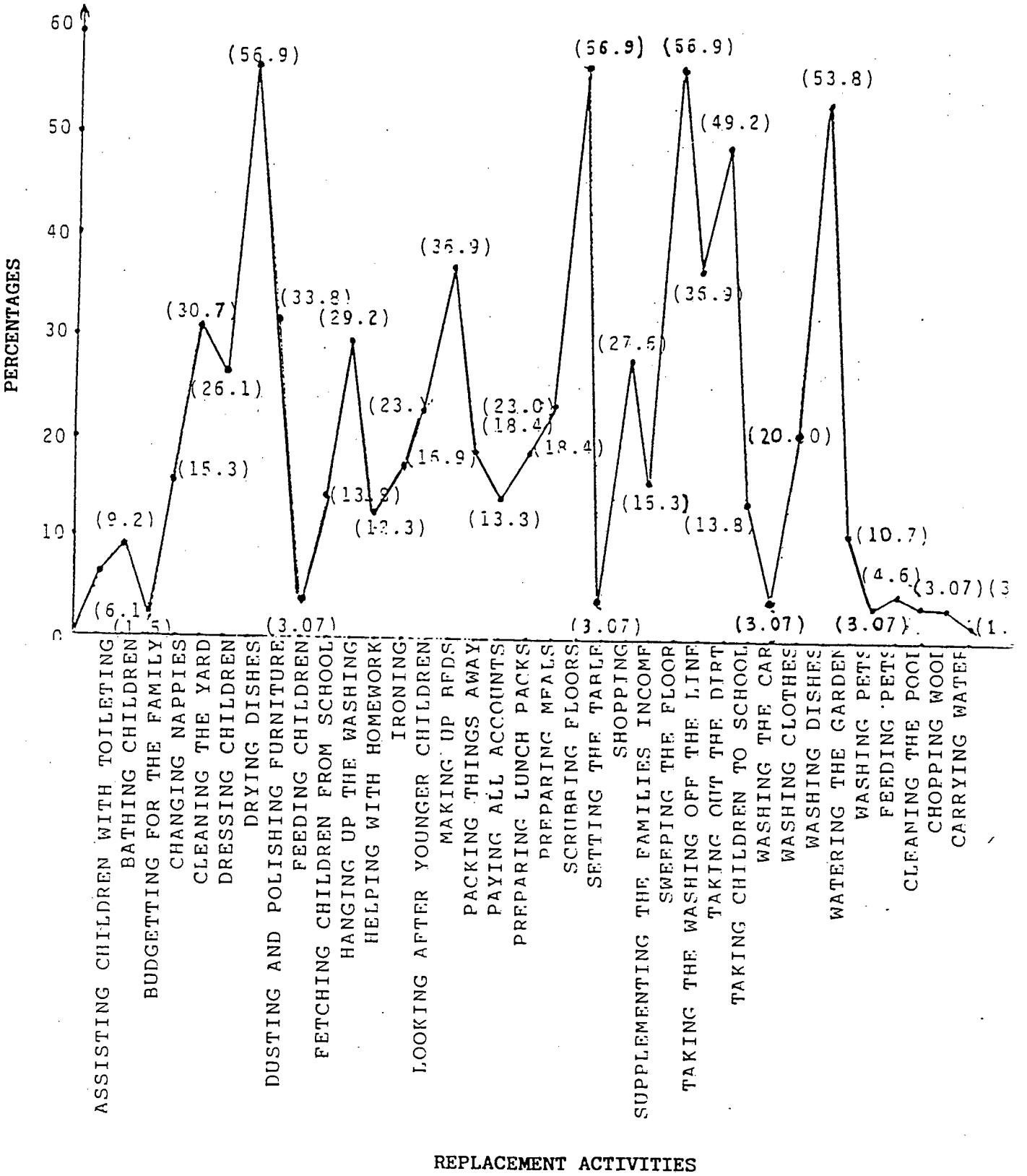
5.7.3 GRAPH: TYPES OF REPLACEMENT ACTIVITIES

(cf. 5.7.3 : 91)

The graph consists of 36 different replacement activities. The activities that were most frequently encountered were those of: the drying of dishes (37 respondents); scrubbing of floors (22 respondents); taking out the refuse (32 respondents) and washing of dishes (35 respondents).

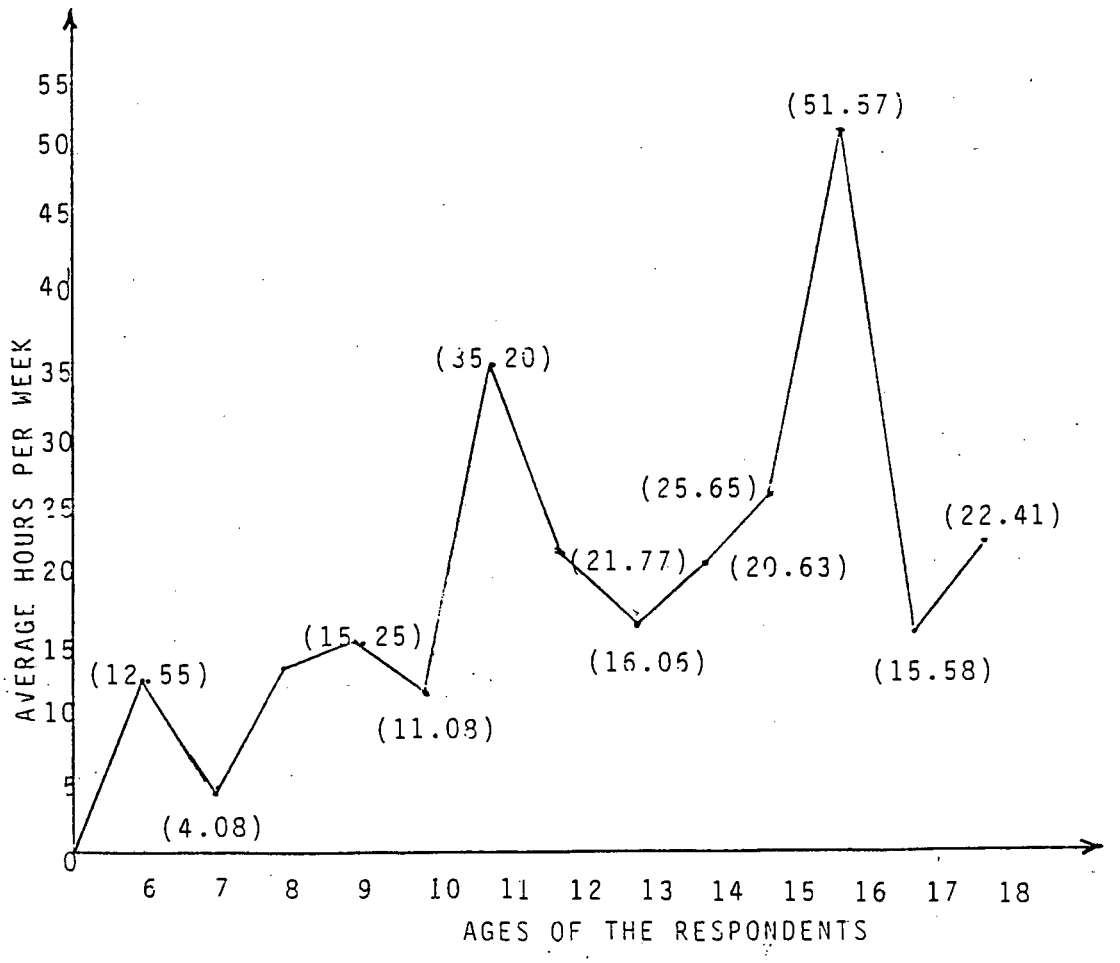
The activities which had the lowest frequencies (under 5%) were: budgeting (1 respondent); feeding siblings (2 respondents); setting the table (2 respondents) and washing the car (2 respondents). The other low frequencies recorded were the categories which the respondents added to the list, which are: washing pets (2 respondents); feeding pets (3 respondents); cleaning the pool (2 respondents); chopping wood (2 respondents) and carrying water (1 respondent). The finding that merits discussion is that in most of the cases the young carers were involved in several house cleaning activities. The researcher, through discussion while administering the interview schedules, discovered that in cases where the physically disabled person was a father or sibling and the mother was the primary carer, the respondents were involved in a wide range of replacement activities. They were not only

5.7.3 GRAPH : TYPES OF REPLACEMENT ACTIVITIES



involved in the sibling/father replacement activities but also in the activities of the mother who, being the primary carer, was unable to do her share of the household activities. There was also another scenario where the father was the physically disabled person and the mother had to be the breadwinner. In this instance, the young carer was involved in both the replacement activities of the mother and the father.

5.7.4 GRAPH: REPLACEMENT ACTIVITIES PRESENTED IN HOURS PER WEEK AND THE AGE CATEGORIES



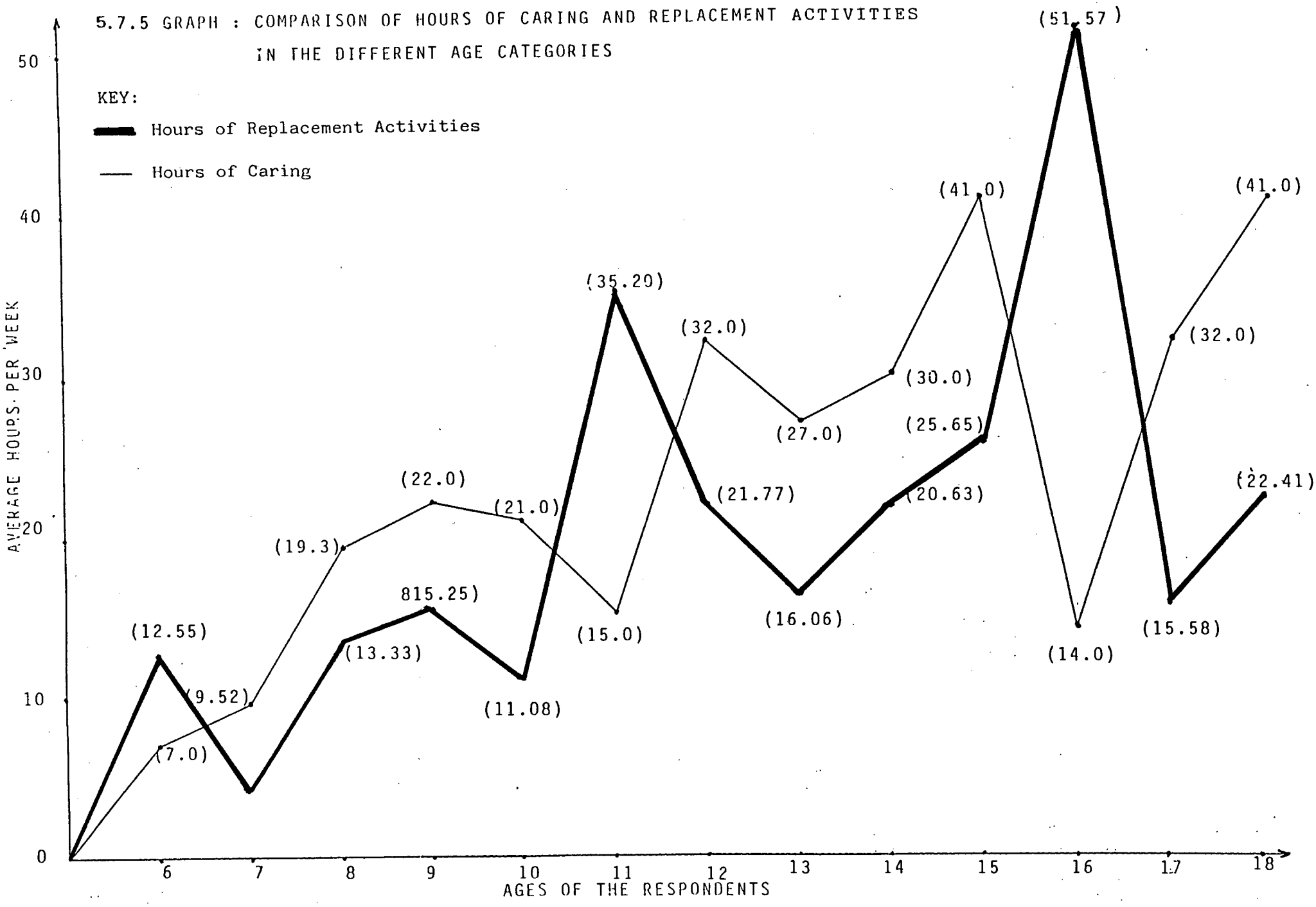
This graph indicates that the 2 categories 11 years and 16 years had the highest frequencies: 35.12 hours and 51.5 hours respectively were utilized per week for replacement activities. The main concentration of respondents was in the 15 to 25 hours of replacement activities per week. 36 respondents were identified in these categories with an average of 19.60 hours per person per week being spent on replacement activities.

5.7.5 GRAPH: COMPARISON OF HOURS OF CARING AND REPLACEMENT IN THE DIFFERENT AGE CATEGORIES

(cf. 5.7.5 : 94)

The age categories 15,16 and 17 years showed a marked difference between the hours spent on caring and the replacement activities. In the 15 year old category the average hours of caring per week was 41.0 hours and the average hours spent on replacement activities were 26.65 hours. These hours together were equal to 66.65 hours per week. The researcher did not set a baseline for hours spent on replacement activities but these 66.65 hours would be considered to be inappropriate in terms of time and age.

5.7.5 GRAPH : COMPARISON OF HOURS OF CARING AND REPLACEMENT ACTIVITIES IN THE DIFFERENT AGE CATEGORIES



Initially 3 of these respondents were not involved in inappropriate caring, in terms of time, but now all 5 respondents in this age category are involved in inappropriate caring, in terms of time because the replacement activities are as a result of the physically disabled person.

The closest interval was in the 6 year old category where the average hours spent on caring was 7.0 hours and replacement activities was 12.55 hours. This means that 19.55 hours were spent on the two activities per week which was significantly lower than the baseline of 28 hours per week for only one of these activities. On the whole, this graphic representation indicates that where hours spent on caring is a considerable amount, the hours spent on the replacement activities are usually a relatively smaller amount.

The reverse is also true, as seen in the 16 year category where the hours spent on the caring activities per week was only 14.0 hours which was considered to be reasonable, but the hours spent on replacement activities were excessive (51.57 hours per week) and means that this young carer spends 65.57 hours on these activities. That means out of the 168 hours in a week, 39.8% (65.57 hours) of the time

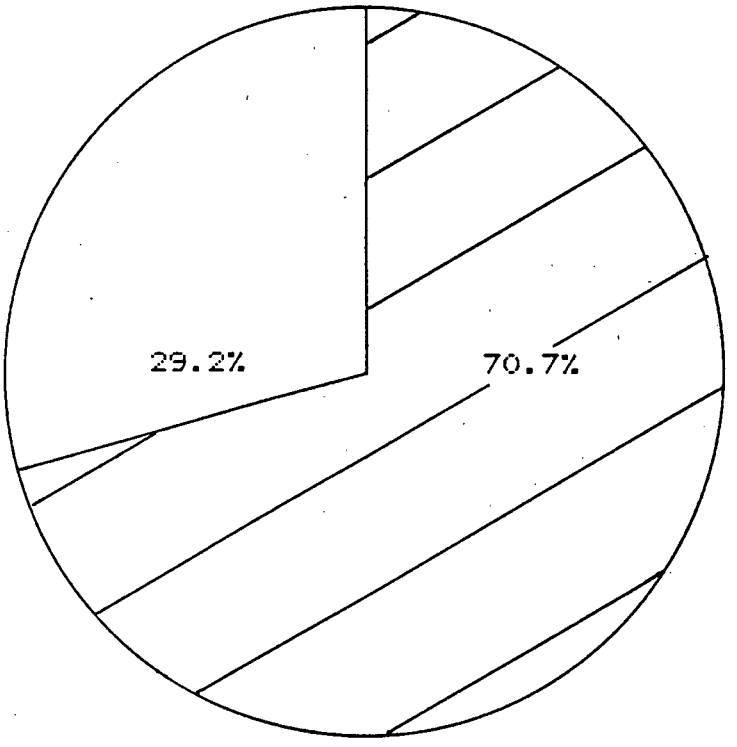
was being spent on caring and 20.8% (35 hours) was spent on going to school per week which is equal to 60.6%. This leaves 39.3% of the hours in the week for 8 hours per night sleeping which is equal to 33.3%. This leaves an impossible 12 hours per week for eating, homework, bathing to list a few vitally essential activities in the life of a child between the ages of 6 years and 18 years. According to this graph all young carers of 8 years (57 respondents) and over are caring inappropriately because of the time factor.

The researcher has now dealt with all the inappropriate types of caring and the replacement activities.

5.8 GENERAL

There was some general information which the researcher was able to establish about the young carers.

5.8.1 PIE CHART: DID SOMEONE SHOW YOU HOW TO CARE



KEY

NO =

YES =

46 respondents were shown how to care. 45% of this number were told by the physically disabled person what to do. 37% of the respondents were shown how to care by the able bodied family members. The remaining 18% were either shown by the district nurse or a physiotherapist at the hospital.

5.8.2 TABLE: LENGTH OF CARING

YEARS	NO OF RESPONDENTS	%
1 - 2	18	27.7%
3 - 4	20	30.7%
5 - 6	9	13.8%
7 - 8	5	7.7%
9 - 10	7	7.7%
10 +	8	12.4%
	N = 65	100

The majority of respondents (20) had been caring for 3 to 4 years. The second highest frequency was in the 1-2 years category (19). Therefore 58.4% of the respondents were caring 4 years and under: 19 (29.2%) respondents have been caring for 10 years and under; 12.3% have been caring for more than 10 years.

5.8.3 TABLE: HELP NEEDED

HELP NEEDED	NO OF RESPONDENTS	%
YES	27	41.5%
NO	38	58.5%
	N = 65	100

Many of the respondents (58.5%) said that they did not need help. They felt that this was a family matter and outsiders were not needed. A few respondents said that their families had to take on this challenge of caring because it was seen as God's will. An 18 year old respondent told the researcher that as she grew up she knew that as each of her 3 elder sisters left home to get married the caring would be passed on and she would get her turn, she said she had a sister of 16 years who would now already been shown how to care for their quadraplegic mother when it becomes her turn.

5.8.4 TABLE: TYPES OF HELP NEEDED

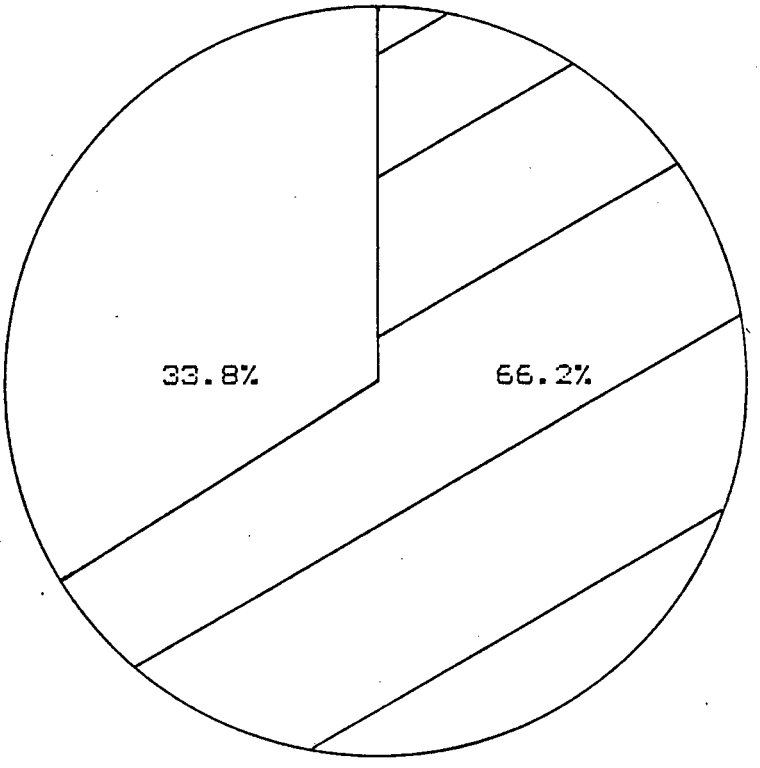
TYPES OF HELP	NO OF RESPONDENTS	%
BATHING	12	44.4%
BANDAGING PRESSURE SORES	1	3.7%
CHANGING SANITARY TOWELS	2	7.4%
DRESSING	1	3.7%
HOLIDAY PROGRAMME	1	3.7%
HOSPITAL VISITS	2	7.4%
LIFTING	21	77.7%
LISTENING AND TALKING	3	11.1%
LOOKING AFTER THE PERSON	4	14.8%
PREPARING MEALS	1	3.7%
REPLACEMENT ACTIVITIES	1	3.7%
SCHOOL WORK	7	25.9%
TOILETING	7	25.9%
TURNING THE PERSON	1	3.7%
WALKING	2	7.4%
WASHING THE PERSON'S CLOTHES	2	7.4%
WHEELCHAIR	2	7.4%
WOOL FOR HOME INDUSTRIES	1	3.7%

The respondents were exceptionally hesitant to ask for help. Sometimes after the interview was completed help would be sought, as if it was an afterthought. A request for assistance with lifting the physically disabled person drew the largest response (77.7%) out of the 27 respondents who requested help. The next highest response (44.4%) was for assistance with bathing the physically disabled person. The young carers in some instances wanted help to make the physically disabled person more comfortable. There were requests for wheelchairs in two instances where there was no wheelchair. One young carer requested wool so that his sister could occupy herself. There were also requests for arrangements for hospital visits as a result of transport difficulties - this appeared to be a problem for the young carers. There were also 3 (11.1%) requests for someone to just talk and listen: a 14 year old complained that after all her chores she was too tired to sit and talk, she needed that time to sleep. There were also requests from 4 respondents for someone to look after the physically disabled person while they were sick. Two young girls aged 9 years and 18 years, said that then they would be able to attend school more regularly. A 15 year old also said she was a religious person and would like to go to church so she would appreciate 2 hours relief per week. This young carer

was spending 82 hours per week caring for her sickly paraplegic mother, as she was the only dependent her mother had.

A 10 year old boy asked for some form of school holiday programme because he would like to go out, as they very rarely had the opportunity of going on outings. He spent 34.15 hours per week caring for his paraplegic mother. 7 (25.9%) respondents asked for assistance with their school work because they are not making progress. One 15 year old boy had failed standard 6 twice and was particularly concerned but he said he did not have time for extra attention despite his request for help. 22 (81.5%) respondents asked for help with inappropriate types of caring activities. 24 (88.8%) respondents who are involved in inappropriate caring in terms of weight asked for help with lifting, turning the person and assisting the person with walking.

5.8.5 PIE CHART: YOUNG CARERS AS PRIMARY CARERS



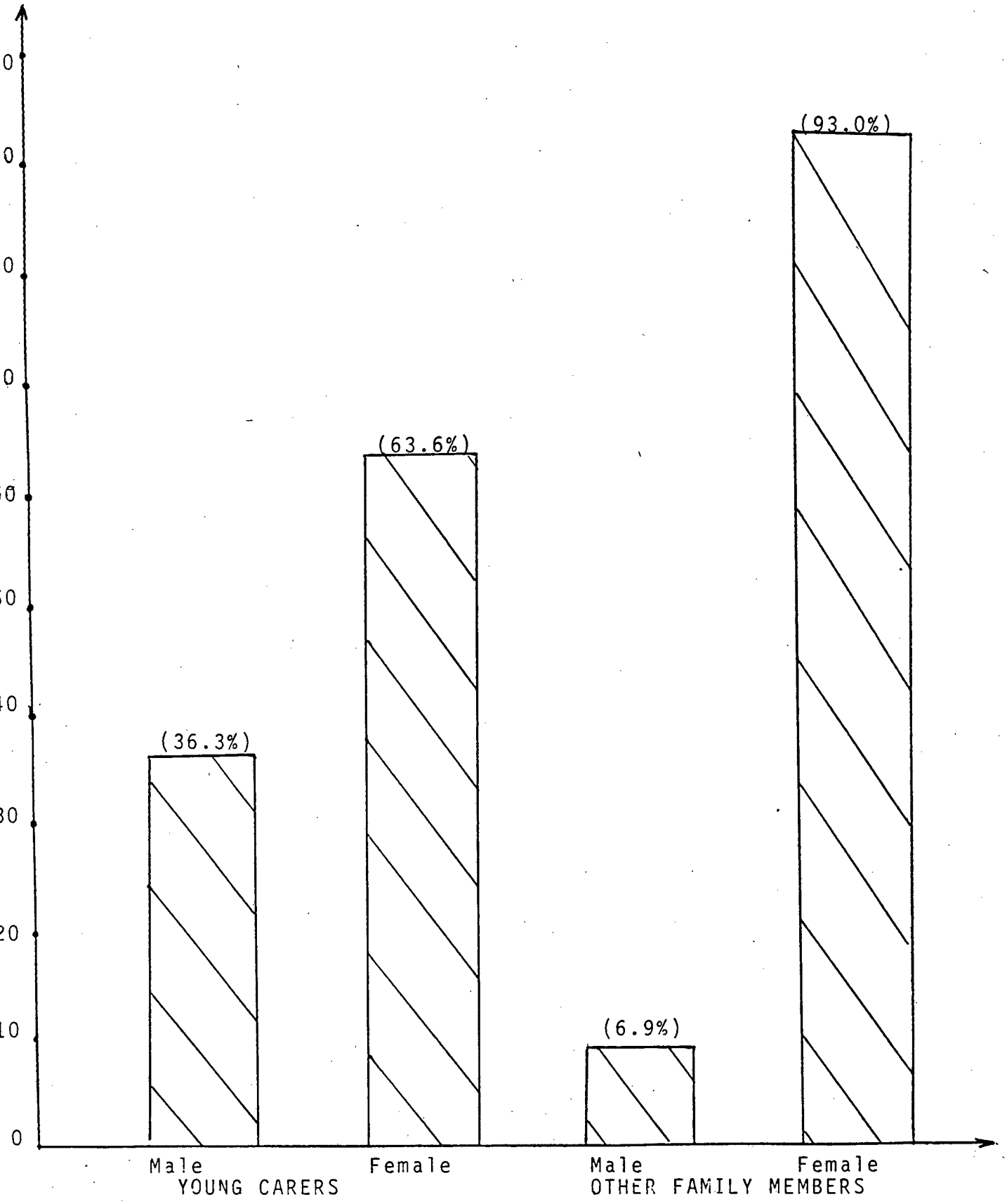
KEY

PRIMARY CARERS =

PERIPHERAL CARERS =

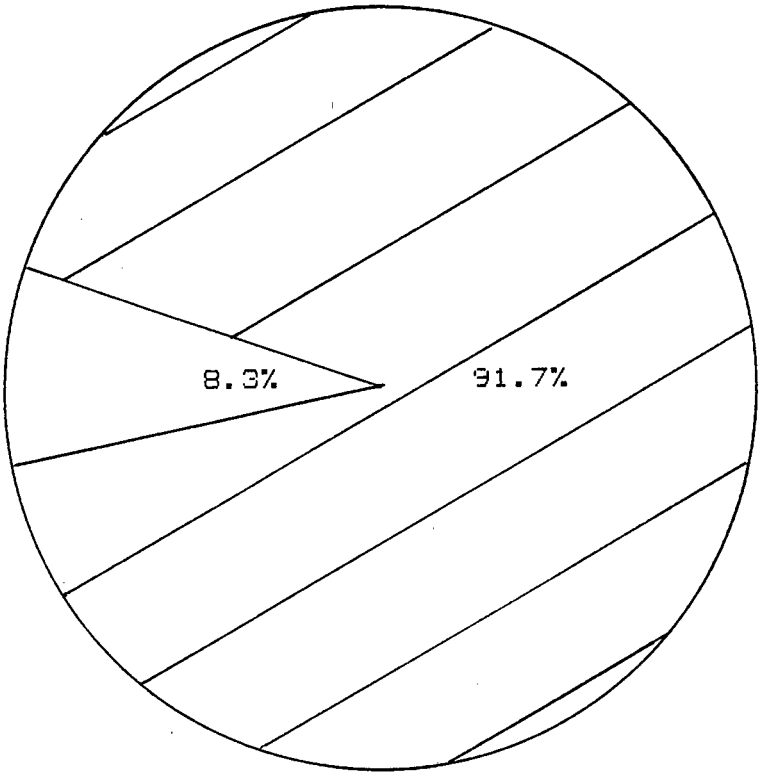
22 (33.8%) respondents were identified as primary carers. The remaining 42 (66.2%) respondents were all peripheral carers. This supports the international literature in chapter 2 (cf. 2.4.1 : 18).

5.8.6 HISTOGRAM: PRIMARY CARERS



As the researcher has already stated 22 respondents were identified as primary carers. To further analyze this the researcher wanted to identify if there were more female than male primary carers in this group. Of the 33.8% the female young carers giving primary care was 63.6%, the remaining 36.3% being male. During the course of the interview the young carers had also identified who was the primary carer, in their opinion. In the other 43 cases (66.2%), the females were the main source of primary care, sisters and mothers looked after the physically disabled persons. This confirms the findings of the Sandwell research (cf. 2.4.2 : 19). These statistics have confirmed what has been said in some of the literature that females form the majority of primary carers as was seen in Equal Opportunities Commission - research report (1982). (cf. 2.3.2. : 14) If there is not a mother, then there is a sister or grandmother. This is a thought provoking issue which could form the basis for further study.

5.8.7 PIE CHART: NUMBER OF RESPONDENTS WHO RECEIVE SCHOOL HOMEWORK



KEY

NO HOMEWORK =

HOMEWORK =

In the beginning of this chapter (cf. 5.1.3 : 55) it was stated that only 60 (92.3%) respondents were scholars: of the 60 only 55 (91.7%) respondents received homework. The remaining 5 (8.3%) respondents were in Sub A and Sub B where homework is not necessarily allocated.

5.8.8 TABLE: TIME SPENT ON SCHOOL HOMEWORK

MINUTES	NO OF RESPONDENTS	%
1 - 60	37	67.3%
61 - 120	9	16.4%
121 - 180	7	12.7%
181 - 240	1	1.8%
241 - 300	1	1.8%
	N = 55	100

This table highlights that the majority of the respondents (67.3%) only use one hour and under for their school homework. 20 of the 60 respondents were in high school (cf. 5.1.4 : 56) and it is expected that they would spend more than 2 hours on their homework as stated in chapter 2 (cf. 2.8.4 : 36). Only 9 (16.3%) respondents spent more than 2 hours (120 minutes) on their homework. The significance of this fact did not receive any specific attention in this research but should be incorporated in any further studies.

The researcher has now completed the analyses of the data collected. The next chapter will include the researcher's recommendations and conclusion.

CHAPTER SIX

6. RECOMMENDATIONS AND CONCLUSION

The researcher has found this area of research to be an enormous challenge. The consolation, in a way, is that the researcher was not incorrect in the researcher's initial assumptions. The findings of the previous chapter have produced the evidence that young children, defined in this research, as young carers are indeed involved in inappropriate caring.

The researcher is not apportioning blame to either, the parents or service delivery organisations, at this point, because the inappropriate caring has come about by force of circumstances and no specific statutory ruling exists on these situations.

Currently, there is ignorance with regard to the needs of the physically disabled persons in this country. For example, the battle continues for accessible buildings, to mention just one area of concern. Seen in this context, it might be understandable that adult carers have received an insignificant amount of attention and that "young carers" are still an unknown entity.

It has become evident from this research that young carers do need help, even if, at this stage all the respondents were not confident enough to ask for some form of relief. The severity of the physical disability will dictate to what extent and what amount of time the young carer will spend on inappropriate caring.

The Association for the Physically Disabled (Western Cape) has a Care Attendant Scheme which is one way of assisting the family members of the physically disabled person. At the moment, only 36 families in the magisterial districts of Wynberg, Cape Town, Athlone areas are benefiting from this much needed service. At the moment only males are receiving care. The lack of expansion has been primarily due to the state department's debate on the issue of subsizidization. The research covered a vast area as outlined in chapter 3 (cf.3.2.2 : 40) and the need has been expressed from many of these areas, ranging from the immediate northern suburbs to the rural areas.

Locally, the organisation also has a carers' support group, which has thus far only targeted adults. There is also the Independent Living Centre - a project of the Association which offers advice and a variety of assistive devices to make the physically disabled persons more comfortable and

also, to make the carer's burden more manageable. The centre also presents seminars to carers on lifting and turning the physically disabled person. The problem the researcher has encountered here, is that it is not accessible to young carers because the seminars are held on week-day mornings during the school term.

Some of the information gathered in the document, at times disturbed the researcher. The sight of a 7 year old boy, unswervingly caring for a severely physically disabled mother and helping her onto a bedpan with extreme effort is a reality fraught with contentious issues. Another example to add to this, is that of a 12 year old girl assuming total responsibility for the disabled person and siblings and maintaining a home with all the essential chores. When asked if she needed help, her only request was that, if it was at all possible, she would be extremely grateful if someone could just sit and talk to her mother because she does not have the time.

Additional research is required to further examine the cursory findings presented in this document. There is little doubt that young carers are essentially vulnerable and that more sophisticated psycho-social evidence is called for to establish the criteria for young carers.

The findings indicated that the majority of children (69.2%) (cf. 5.5.3 : 75) were involved in inappropriate caring in terms of weight. This suggests that attention should be paid by physiotherapists and other professionals not only to the physically disabled person but also to the family members who are considered to be the carers in order to prevent creating further physical disabilities in the form of back injuries.

Inappropriate caring in terms of time (per day) indicated that 35 respondents (53.8%) were involved (cf. 5.4.2 : 66). In terms of hours spent caring per month 55.3% of the respondents were involved (cf. 5.4.4 : 69). This does not appear to be a large number, just a little more than half. 35 respondents spent more than 4 hours caring per day. The statistic changes dramatically when one considers the hours spent on replacement activities. The initial 35 respondents involved in inappropriate caring in terms of time becomes 57 respondents when the hours spent on replacement activities are added. The researcher did not establish a baseline for the hours spent on replacement activities (cf. 5.7.2 : 88) . The graphic presentation (cf. 5.7.5 : 94) indicates that all children over the age of 8 years are involved in time inappropriateness because caring

time and replacement time would then be over 28 hours per week. The same effects will apply as has been stated in chapter two (cf. 2.8.4 : 35) with regard to inappropriate caring in terms of time. A young carer, as a result of constantly being 'on duty' has no leisure time. The researcher sees the major causal factor for excessive hours spent on replacement activities as being a result of the replacement of mother's activities. The study has evidenced that out of the 65 respondents, 27 respondents (41.5%) were doing replacement activities for mothers. (cf. 5.7.2 : 89) This represents almost half of the respondents.

The researcher has already mentioned the Association for the Physically Disabled (Western Cape) Care Attendant Scheme's limitation with regard to the area it serves. (cf. 6 :109). Another limitation which is perhaps, one that now with this evidence, should receive urgent attention, is that there are no female care attendants hence no female clients are receiving this essential service. This research indicated that where there are mothers incapacitated, the replacement activities are so much more demanding. Young carers, caring for their mothers should become a priority, for some form of relief provision.

An additional significant time issue that was examined was time spent on homework. For this study, the researcher alluded that the time spent on caring effected the time spent on homework. The majority of the respondents (37) spent one hour or less on homework. Bearing in mind that 21 respondents were in senior secondary school, only 9 respondents spent 2 hours and more on homework. The baseline for homework for senior secondary children was set at two hours (cf. 2.8.4 : 35). The fact that only half of the respondents (50.8%) were involved in inappropriate types of caring activities does not minimize this unsatisfactory situation. (cf. 5.3.1 : 61). There are other findings which merit attention before the researcher can make relevant recommendations. Female young carers (63.6%) formed the most primary young carers, out of the 22 primary young carers (33.8%) identified (cf. 5.8.5 : 103).

The majority of the respondents were from lower socio-economic communities and only 3 respondents had paid home-help. It was evidenced, that in the addition to the caring activities, the young carers also had to do all the housework. The researcher did not ask specific questions on the overall financial status of the family but ten young carers were also working in the afternoons or weekends to

supplement the family's income. This could be because the physically disabled person is a grantee.

The researcher hopes that further research will be conducted to prove that severely disabled persons should have more than the prescribed attendant allowance. Provision should actually be made for paid domestic services for the whole week. For this reason, the present R50.00 per month is considered inadequate.

6.1 RECOMMENDATIONS

Against the backdrop of the research findings the researcher wishes to suggest the following recommendations to the Association for the Physically Disabled (Western Cape) and its branches, other organisations and institutions, who render services to the disabled, frail and chronically ill, and the relevant state departments.

The recommendations are as follows:

6.1.1 That an awareness campaign be initiated to assist in identifying young carers.

6.1.2 That a central register of young carers be kept at the organisations and institutions mentioned above, with the aim of establishing a carers support organisation.

6.1.3 That professionals acquaint themselves with the plight of young carers.

6.1.4 That in instances where young carers are identified as the primary carers, social workers and other professionals of the relevant organisations and institutions make alternative arrangements.

6.1.5 That a workshop be held to enable young carers to define their needs on a broader base.

6.1.6 That seminars on lifting, turning, et cetera, be organised, as is being done by the Independent Living Centre but that it be made more accessible to young carers in terms of weekends or school holidays.

6.1.7 That further in-depth research be conducted on the subject of young carers.

6.1.8 That the community be encouraged to start voluntary informal attendant care projects along the prescribed ideology of community based rehabilitation.

6.1.9 That the present attendant allowance be increased in the cases where the physically disabled person is severely disabled, to enable payment of full time domestic worker.

6.1.10 That the state departments subsidizes existing care attendant schemes to enhance expansion and further, initiate more care attendant schemes.

6.1.11 That the Association for the Physically Disabled (Western Cape) expands their care attendant schemes to include its branches and female clients

6.2 CONCLUSION

This research has just drawn back the covers on what is known as the informal family care network. Young carers

have been in this role for a very long time. Some as long as 14 years. One 7 year old proudly told the researcher that while he is at school his 4 year old sister looks after his mother who has multiple sclerosis and his two year old sister. The researcher had interviewed children between the ages of 6 to 18 years but it is comments like this, that needs further investigation.

This research has been an attempt to pose the first formal questions with regard to the caring activities of children in relation to the physically disabled.

The researcher hopes that this document has sown the initial seeds of awarenes in the minds of a previously uninformed society. Society has to take responsibility to ensure the rights of children and to protect them from neglect. Abuse comes in different formats, disruptions to a child's scholastic activities and lack of play and peer associations as a result of having no time, could amount to being yet another format.

In instances, where there are young carers, with training and guidance they can indeed take on the role of a carer but in a peripheral sense which means offering the primary carer assistance or relieving this person for an hour or

two, occasionally.

Built-in support has to be provided which would serve a dual purpose: of offering support and also serving as a regular check to ensure that the caring provided by these children are still within the bounds of appropriateness.

Professionals attached to the various service organisations would be in a perfect position to monitor the appropriateness as part of their services to the disabled person and, equally important, the family members of the physically disabled persons.

In conclusion the researcher would like to leave the reader with a clear picture of the reality. Based on this research, children between the ages of 6 and 18 years inclusively, in the Western Cape are involved in inappropriate caring for the physically disabled.

The researcher has made several recommendations to all the professionals and social service delivery organisations. It is hoped that, at least some, if not all of these recommendations will be favourable received with the view to possible implementation to ease the plight of young carers.

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APPENDIX 1

CONSTITUTION

1. NAME

1.1 The name of the Association is the Association for the Physically Disabled (Western Cape) (Constituent member of the National Council for the Care of Cripples in South Africa)

1.2 The Association is a constituent member of the Western Cape Council for the Physically Disabled.

2. OBJECTS

2.1 To protect and promote the interests of all physically disabled persons with loco-motor handicaps referred to hereafter as disabled persons

2.2 To promote and/or support measures which will prevent or reduce the occurrence of disabling conditions and their effects.

2.3 To promote, undertake and/or support community projects concerned with medical, educational, vocational, social and recreational rehabilitation of disabled persons

2.4 To promote and/or undertake activities which will improve the physical and social environment, including public facilities, to the advantage of disabled persons

2.5 To establish and maintain a comprehensive social work service.

2.6 To encourage a greater concern, understanding and awareness among the general population of the handicaps and difficulties of disabled persons

2.7 To encourage and facilitate the formation of committees, branches,

2/....

local associations or other administrative bodies to carry out these objects either in specific geographical areas or for specific functions

2.8 To co-ordinate the work of all organisations engaged or interested in the welfare of the physically disabled generally and to influence the decision of local and provincial authorities so that these objects may be achieved

2.9 To be the official channel of communication between this region and the National Council for the Care of Cripples in S.A.

3. SERVICE

To disabled of all population groups and ages

4. SERVICE AREA

South Western area of the Cape Province including and bounded by the following magisterial districts : George, Oudtshoorn, Prince Albert, Beaufort West, Victoria West, Carnarvon, Calvinia, Williston and Namaqualand and along West Coast and Southern Coast to aforementioned boundaries; and magisterial district of Walvis Bay

5. MEMBERSHIP

Membership shall be open to any interested person.

Members may fall into the following categories:

5.1 HONORARY OFFICE BEARERS:

At an Annual General Meeting members may elect an Honorary President and Honorary Vice Presidents from members of the Association. The Honorary President and Honorary Vice Presidents

3/.....

shall be ex-officio members of the Management Committee

5.2 HONORARY LIFE MEMBERS:

At an Annual General Meeting members may, on the recommendation of the Management Committee, elect any member as an Honorary Life Member in recognition of special services rendered to the Association or to the welfare of the physically disabled generally in or beyond the service area

5.3 LIFE MEMBERS:

A contribution as determined by the Annual General Meeting shall qualify the donor for Life Membership

5.4 INDIVIDUAL MEMBERS:

An annual subscription as determined by the Annual General Meeting paid either to the Association or a Branch shall qualify the donor for membership

A member shall not exercise his/her rights of membership at an Annual General Meeting or other meeting of the Association unless the subscription has been paid at least one month before the date of such meeting. The Director shall keep a register of the names and addresses of all members

6. LIABILITY OF MEMBERS

The individual members of the Association shall not be responsible or answerable for the debts, obligations or engagements of the Association in their personal capacity

7. AFFILIATION

Other organisations with similar interests may apply to affiliate

to the Association. If accepted they shall be liable to an annual subscription as determined by the Annual General Meeting

The Association may affiliate to other organisations with similar objects

8. MANAGEMENT

The Management of the Association shall be by a Management Committee

8.1 The Management Committee shall consist of -

a Chairman

two Vice-Chairmen

a Treasurer

not less than 3 and not more than 11 other members elected at an Annual General Meeting

8.1.1 Any member of the Management Committee who fails to attend three (3) consecutive meetings without leave from the Committee shall ipso facto cease to be a member of the Committee. Such a vacancy or any other vacancy as a result of resignation or death shall be filled by a person appointed by the Management Committee until the Annual Meeting of the Association

8.1.2 Paid officials of the Association may be members of the Management Committee with the right to speak but not to vote

8.1.3 The Management Committee shall meet at least ten (10) times per annum

8.1.4 The Director shall give members at least 10 days written notice of a Management Committee meeting

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8.1.5 The quorum at such meetings shall be half the members

8.1.6 In the event of there not being a quorum present, the meeting shall continue. Decisions taken shall be ratified at the next meeting when a quorum is present

8.1.7 In the absence of the Chairman, one of the two Vice-Chairmen shall preside. In the event of these officials being absent for a particular meeting, the Committee shall appoint a Chairman from its members, with a vote for that meeting, which Chairman shall only be elected from those members who have voting rights

8.1.8 A simple majority of all those members with voting rights present at a Management Committee Meeting shall be necessary to carry out any decision or pass any resolution

8.1.9 The presiding member shall have a casting as well as a deliberative vote

9. POWERS OF MANAGEMENT COMMITTEE

9.1 To acquire, hire, exchange, mortgage, encumber, let, dispose of or otherwise deal in movable and immovable property and rights of any description

9.2 To collect and raise monies by way of bequests, donations, grants, collections or any other approved manner

9.3 To maintain and improve immovable property and to build and/or renovate and/or demolish any building or other structures thereon

9.4 To accept any donation in kind

9.5 To raise or borrow money including by way of overdrafts for the purpose of the Association

6/....

9.6 To invest money which is not immediately necessary for the objects of the Association in State or Municipal securities or in interest bearing accounts in bank and building society institutions; to retain investments in equities received by way of bequests

9.7 To appoint and dismiss staff and to draw up service contracts

9.8 To enter into contracts and agreements for the use and benefit of the Association

9.9 To institute and defend actions and proceedings at law

9.10 To appoint sub-committees which may include paid officials

9.11 To establish branches as required. A branch shall be constituted by not less than 5 persons who carry out the functions and activities of the Association within a particular geographic or functional area. The Branches shall be obliged to carry out the policy of the Association, to accept professional supervision in the social work field and any inspection which may from time to time be considered necessary by the Management Committee

9.12 To carry out any other activities necessary for administering the Association, which shall include the co-opting of additional members to the Management Committee

9.13 To pass resolutions

10. DUTIES OF MANAGEMENT COMMITTEE To ensure that -

10.1 Minutes of the Meetings of the Management Committee are kept, and that the names of all members present and who have apologised are recorded therein

7/.....

10.2 All monies received by the Association are promptly and without abatement deposited in a bank account/s registered in the name of the Association

10.3 Proper books of account are kept which reflect financial activities of the Association including the acquisition or disposal of any movable or immovable property

10.4 All payments are approved by the Committee. Payments of more than One hundred Rand (R100) are paid by cheque signed by two of the following -
Hon. Treasurer or Chairman or one of two committee members appointed by resolution of the Management Committee for this purpose and
The Director or (if absent) a senior member of staff appointed by special resolution of the Management Committee for this purpose.
Other payments may be authorised and signed by the Director or (if absent) a senior member of staff

10.5 An audited balance sheet and statement of income and expenditure is submitted to the authority as stipulated in the Fund Raising Act No 107 of 1978

10.6 No funds are raised by the Association for any other purpose except for those laid down in the constitution and no money or property is used for any other purpose

10.7 All documents and statements of accounts are retained for a period fixed by resolution of the Management Committee and not less than three (3) years after audit

10.8 All accounts, books, registers and minutes of meetings are avail-

able for inspection by members of the Management Committee, the Director and any statutory officials

10.9 Names and addresses of Committee Members are submitted to the Secretary of the Regional Welfare Board

11. ASSETS

11.1 All property, movable and immovable, owned by the Association shall be registered in the name of the Management Committee on behalf of the Association

The Management Committee shall have the powers referred to in Clause 9.1 above

11.2 TRUSTEES

11.2.1 The Trustees of the Association shall be the Chairman, Vice-Chairmen and Treasurer. The Management Committee shall have the power to fill any vacancy in the office of Trustee

11.2.2 The Trustees of the Association in terms of Resolution by the Management Committee shall have power to sign and execute all necessary documents to enable transfer to be taken or passed of property so bought or sold, disposed, mortgaged or pledged, provided a Resolution granting them the necessary authority is passed by the Management Committee

Whenever required, Resolutions may be certified by two of the following:

The Chairman and failing him, a Vice-Chairman and Treasurer and failing him, the Director

11.2.3 All income and assets of the Association from whatever

9/....

source shall be used only for the promotion of the objects of the Association as laid down in Clause 2 above. No portion thereof may directly or indirectly by way of dividend, bonus or any other means be paid or transferred to members of the Management Committee, or any other similar person other than by way of the payment in good faith of reasonable remuneration to any officer or employee of the Association for any services rendered to the Association.

12. ANNUAL GENERAL MEETING

12.1 The Management Committee shall arrange an Annual General Meeting of members as soon as possible after the end of each financial year

12.2 The Director shall give members at least 21 days notice of an Annual General Meeting. The notice shall include an Agenda which must include -

12.2.1 Presentation of Annual Report and audited Financial Statements for approval

12.2.2 Appointment of Management Committee

12.2.3 Appointment of auditor who shall be a Chartered Accountant

12.2.4 Any other business about which written notice in terms of (12.2) has already been given

12.3 The quorum for the Annual General Meeting shall be 25 members

12.4 In the event of there not being a quorum present, the meeting shall be adjourned for seven (7) days. The members present at such an adjourned meeting shall constitute a quorum.

The Hon. President shall preside at the Annual Meeting.

12.5 In the absence of the President, the Chairman or one of the Vice-Chairmen shall preside. In the event of all of these office bearers being absent the meeting shall appoint a Chairman from amongst its members by simple majority vote

12.6 Honorary office bearers, Honorary Life members, Life members and Individual members who have paid their subscriptions (see clause 5.4) have the right to vote. In the event of an equal vote the Presiding Officer has a casting vote

12.7 Save for provisions in Clause 16 and 17.1 all the decisions shall be taken by a simple majority vote

12.8 At an Annual General Meeting each member shall be entitled to one vote, such vote may be written, by proxy or otherwise as may be determined by the Committee, and the vote of the majority of the members present or represented at any properly constituted meeting shall be deemed to be the decision of the meeting: provided that no person other than a member duly authorised in writing shall represent any member or members at any such meeting

12.9 The financial year shall be from the 1st April to the 31st March each year

13. A SPECIAL GENERAL MEETING

May be called by the Management Committee or by any fifteen (15) members eligible to vote at such meeting, on requisitions signed by them, addressed to the Director and stating the business which they desire to be considered at such meeting. At least ten (10) days' notice of such meeting shall be given in writing by the Director to all members of the Association. Such notice shall state the business to be brought before

such meeting. The business of which notice shall be given shall include the business stated in the requisition and may also include other business specified by the Management Committee

14. COMBINED BRANCH MEETINGS

14.1 The Management Committee shall arrange meetings of Branch representatives, including Cape Town, at least once per year or more often as required

14.2 A combined Branch Meeting shall serve as a forum for discussion between Branches and to propose resolutions for the attention of the Management Committee

14.3 The Chairman of the Management Committee shall be the Chairman or failing him one of the Vice-Chairmen. In the event of all these officials being absent, the meeting shall appoint a Chairman from those members present

14.4 A quorum at a combined Branch Meeting shall be at least half the numbers of Branches including Cape Town

14.5 Each Branch shall have one vote irrespective of the number of its representatives attending the meeting

14.6 The Chairman shall have a casting vote in addition to a deliberative vote if he represents a Branch

15. COUNCIL MEETINGS

15.1 The Management Committee shall arrange meetings of the Council at least once per year or more often as required

15.2 Council Meetings shall serve as a forum for discussion between Affiliate Organisations, relevant State Departments, Provincial

12/....

and Local Authorities, Branch Representatives and the Management Committee, and to propose resolutions for the attention of the Management Committee.

15.3 The Council shall be composed of the following representatives:

The Chairman of the Management Committee, or failing him one of the Vice-Chairman.

2 representatives from each of the Branches, including Cape Town, where the representatives should be drawn from the Management Committee.

1 representative from each Affiliated Organisation.

1 representative from each of the relevant State Departments, Provincial and Local Authorities.

15.4 The Council shall elect its own Chairman from those representatives present at the meeting.

15.5 A quorum at a Council meeting shall be more than half the combined number of Branches and Affiliated Organisations registered with the Association.

15.6 Each Branch or Affiliated organisation shall have one vote; representatives of State Departments, Provincial and Local Authorities shall take part in discussion, but shall have no voting powers.

15.7 The Chairman shall have a casting vote in addition to a deliberative vote if he represents a Branch or Affiliated Organisation.

16. AMENDMENT OF CONSTITUTION

The Constitution may be amended at the Annual General Meeting or at a Special General Meeting. No alteration or addition shall be considered unless at least one (1) month's notice thereof has been given to all members.

13/....

Such notice may be given by ordinary post. The notice convening any such meeting shall specifically state the nature of the amendments to be proposed and the reasons therefor.

A two-thirds (2/3rds) majority of all present at such meeting shall be necessary to carry any proposed amendment.

7. DISSOLUTION

17.1 The Association may be dissolved if at least two-thirds (2/3rds) of the members present and voting at a General Meeting of members convened for the purpose are in favour of dissolution.

Not less than twenty-one (21) days' notice shall be given of such meeting and the notice convening the meeting shall state clearly that the question of dissolution of the Association and disposal of its assets will be considered. If there is no quorum at such a General Meeting, the meeting shall stand adjourned for not less than twenty-eight (28) days and the members attending such adjourned meeting shall constitute a quorum.

17.2 If upon dissolution of the Association there remain any assets whatsoever after the satisfaction of all its debts and liabilities, such assets shall not be paid to or distributed among its members but shall be given to one or more of other registered welfare organisations preferably having similar objects, as may be decided by the members at the General Meeting at which it was decided to dissolve the Association.

In default of such decision, assets shall be paid or distributed in accordance with Section 14 of the Fund-Raising Act No 107 of 1978.

APPENDIX 2

The Association for the Physically Disabled, in its Orientation Manuel (1985:1-9) defines the following disabilities:

1. Amputations

An amputation is a surgical removal of limbs. Diabetes is one of the diseases that may result in amputations of one leg/arm or both . Explosions are also another causal factor and can result in bilateral amputations.

2. Cerebral Palsy

This is caused by damage to parts of the brain, before, during or after birth:

i. when not enough oxygen is received by the baby's brain prenatally;
ii. disease of mother, e.g. German measles
iii. blood incompatibility prior to birth (Rhesus Factor)

There are three types of cerebral palsy

a. Spastic - "stiff" muscles, not able to move easily, appears to be paralysed.
b. Athetoid - too much movement which cannot be controlled; arms fly in all directions and walking is accompanied by lurching and staggering.
c. Ataxia - there is lack of balance and direction, the person frequently lose balance in walking and cannot judge distance when lowering him/herself on to a bed or chair.

Their intellect is not necessarily impaired but speech difficulties are experienced.

3. Congential Malformation or Amputation of Limbs

Malformed limbs during prenatal periods, for example, an arm, either above or below elbow, sometimes with small finger protrusions at the end of the limbs or

where a leg where section is underdeveloped, sometimes with part of the foot at end of the limb. The Amelia Syndrome is also catered for under this section which means absence of limbs (legs or arms or both).

4. Gulliane Barre Syndrome

This refers to a disease which may leave the patient paralysed to a varying degree. It is due to an infection of the peripheral nerves; both the motor and memory parts are affected. These persons are often left severely disabled and require extensive appliances.

5. Head Injury

Severe injuries to the skull caused by, for example, MVA's, assaults and brain tumors damage to the brain tissues. The physical paralysis relates to the part or parts of the brain which have been damaged. Frequently there is a period of coma. The paralysis tends to be one-sided hemiparesis. Speech and eye sight are also affected. There is often considerable intellectual impairment.

6. Hemiplegia - Cerebral Vascular Disease - Stroke

A blood vessel in the brain "bursts" and there is a temporary lack of oxygen to that part of the brain causing damage to the brain tissue. Paralysis is to one or other side of the body and the extent of the paralysis varies enormously, from total incapacity to only slight impairment.

7. Huntington's Disease

This is a genetically determined disease which affects the central nervous system. It is a chronic degenerative illness where emotional responses are often impaired. The person can experience involuntary, jerking and twitching movements with mental deterioration leading to dementia. It gradually progresses over a 10 to 20 year period, ending in death.

8. Multiple Sclerosis

This is a gradual deterioration of the nervous system resulting in gradual paralysis. There may be weakness on one side of the face with heaviness of the limbs and partial blindness in one eye or even double vision. The person may experience convulsive seizures or one-sized paralysis. The person could also have tremors and slow speech accompanied with rapid mood swings.

9. Muscular Dystrophy

Gradual weakening of the muscles of the body, often starting with the lower limbs. The patient is unsteady on his/her feet with rather awkward movements of feet and legs, and tends to fall. Total paralysis eventually sets in, ending in failure of muscular contral of the heart and lungs.

10. Osteogenesis Imperfecta

Imperfect formation and mineralization of bone with skeletal deformity. Very frequent fractures occur in childhood and which result in stunted growth, malunion of the fractures with resultant deformities of the limbs. As adults they are often very short and have all limbs stunted.

11. Paraplegia

This is a spinal cord injury. The injury is to the thoracic and lumber regions. Hands and arms are intact, but lower limbs are affected. If the lesion of the spinal cord is incomplete there is the possibility that the person could walk with appliances. Complete lesions lead to the person being wheelchair bound. If the person strengthens their arms they can then do transfers without assistance.

12. Poliomyelitis

Inflammation of the grey substance of the spinal cord. This may result in quadraplegia, paraplegia, one sided paralysis of arms, legs or both. After an acute phase of the illness paralysis may decrease but when initial recoveries have been reached, the condition remains stable thereafter. In many cases caliphers are worn to support weak muscles.

13. Quadraplegia (Tetraplegia)

Spinal injury at levels C4-7. If there is severance of the cord at these levels all four limbs are affected. C4 persons have only very limited use of the hands and arms and are usually unable to feed themselves and write without the use of special hand splints, some even battery operated. There is no bowel or bladder control, they are either fitted with an indwelling catheter which is changed weekly by a nurse, or a urinary bag which is changed daily. Bowel actions are regulated through bowel training. Tetraplegia refers to a paresis of one limb which means there is partial movement in that limb.

14. Spastic Diplegia

It is a chronic illness is caused by foetal prematurity. It refers to a paralysis of like parts on either side of the body. Pertaining to or marked by spasms. It is a form of cerebral palsy and it mainly affects the muscles of the lower limbs. The person has no control over bowel and bladder movements.

15. Spina Bifida

This is a congenital defect of the vertebral column due to an imperfect union of the paired vertebral arches at the midline. It may be so extensive as to allow herniation of the spinal cord and meninges, or maybe covered by intact skin. In some instances this leads to swelling of the head due to excessive fluid, paralysis of the legs and incontinence.

16. T.B. Spine

TB spine can result in severe paraplegia and kyphosis. Kyphosis is defined as abnormal curvative and dorsal prominence of the spine or as backward curvature. Existing cases of severe deformities are the result of lack of treatment. Often spinal fusions are done to prevent further deterioration of the spine and children having undergone adequate, early, treatment now have no visible deformity.

There are still many other types of physical disabilities but for the purpose of this research further definitions will not be required.

APPENDIX 3

(cf. List of Respondents : 140)

KEY

MB V AA	=	Social Workers' initials
F	=	female
M	=	male
CNA	=	children not available
APD	=	Association for the Physically Disabled (Western Cape)
PAPD	=	Paarl Association for the Physically Disabled
TAPD	=	Tygerberg Association for the Physically Disabled
WCAPD	=	West Coast Association for the Physically Disabled
WAPD	=	Worcester Association for the Physically Disabled

NO	CASE	AREA	SAMPLE	BRANCH
MB 2	J.L.	RHOODEVAL	F15,14,13	WAPD
V 9	J.C.	BERGVLIET	M11,13	APD
A 7	R.G.	NEW WOODLANDS	M8	APD
D 12	C.J.	LAAIPLEK	F7,18	WCAPD CNA
CO 4	F.A.	LEONSDALE	F12	TAPD
R 3	M.L.	SCOTTSDENE	M14	TAPD
D 3	J.B.	VREDENBURG	M17,18	WCAPD
S 9	C.B.	NYANGA	M9	APD
I 4	S.W.	RIVERLEA	F16,9 M13	WAPD
V 13	S.C.	HEATHFIELD	M10	APD
A 3	S.M.	PARKWOOD EST.	F17,14 M7	APD
M 4	E.M.	GUGULETU	F14,M17	APD
G 3	R.M.	EASTRIDGE	F18	APD
AA 5	V.B.	PAARL	F6,M9	PAPD CNA
CO 8	R.S.	LEONSDALE	F14,7	TAPD
Z 14	G.K.	MANENBERG	F13	APD
A 5	C.v R.	STEENBERG	F18,12	APD
R 5	F.P.	DELFT	F16,14, F12,8	TAPD
G 5	A.P.	EASTRIDGE	F6	APD
Z 10	M.A.	BONTEHEUWEL	M12	APD
D 1	E.T.	STOMPNEUSBAY	F16,6 M10	WCAPD

I 20	I.K.	WORCESTER	F6, M16	WAPD CNA
L 11	S.V.	DE DOORNS	F15,8,6	WAPD
I 15	R.L.	RIVERLEA	F11,9,7 M14,8	WAPD
L 13	J.D.	DE DOORNS	F10	WAPD
G 15	S.D.	WESTRIDGE	F18, M12	APD
V 19	J.W.	SOUTHFIELD	M6	APD
S 20	P.N.	KHAYELITSHA	M10	APD
AA 2	B.C.	WELLINGTON	F16,10	PAPD
MB 8	W.A.	WORCESTER	M13	WAPD
V 6	C.L.	LANSDOWNE	F8	APD
A 2	I.L.	GRASSY PARK	M14	APD
S 17	M.B.	CROSSROADS	M13	APD
V 15	W.J.	PHILLIPI	M15	APD
CO 9	E.R.	KUILSRIVER	M9	TAPD
V 14	A.D.	WYNBERG	M10	APD
R 12	S.T.	BELHAR	F7	TAPD
G 2	A.G.	EASTRIDGE	M18	APD
L 4	K.W.	DE DOORNS	M10	APD
M 10	J.P.	LANGA	F10	APD
MB 13	A.G.	RHOODEVAL	F15	WAPD
D 5	P.D.	PIKETBERG	F9	WCAPD CNA
		46 cases =	72 children	

UNIVERSITY OF CAPE TOWN

SOCIAL WORK DEPARTMENT

INTERVIEW SCHEDULE: An investigation to determine the appropriateness of care provided by children for physically disabled persons.

A. IDENTIFYING PARTICULARS OF THE YOUNG CARER

1. NAME : .....

2. ADDRESS: .....

.....

3. FILE NO: .....

4. AGE: .....

5. SEX:

MALE	FEMALE

6. ARE YOU A SCHOLAR

YES	NO

IF NO, PLEASE EXPLAIN: .....

.....

7. WHAT STANDARD ARE YOU IN ? .....

8. HOW MUCH DO YOU WEIGH ? .....

B. THE DISABLED PERSON

9. WHAT IS YOUR RELATIONSHIP TO THE DISABLED PERSON ?

a. MOTHER
b. FATHER
c. SISTER
d. BROTHER
e. COUSIN
f. AUNT
g. UNCLE
h. GRANDMOTHER
i. GRANDFATHER
j. OTHER

IF OTHER, PLEASE COMMENT .....

10. WHAT IS THE PERSONS DISABILITY ?

a.	AMPUTATIONS	
b.	CEREBRAL PALSY	
c.	CONGENITAL MALFORMATION OF LIMBS	
d.	GULLIANE BARRE SYNDROME	
e.	HEAD INJURY	
f.	HEMIPLEGIA	
g.	HUNTINGTON'S DISEASE	
h.	MULTIPLE SCLEROSIS	
i.	MUSCULAR DYSTROPHY	
j.	OSTEOGENESIS IMPERFECTA	
k.	PARAPLEGIA	
l.	POLIOMYELITIS	
m.	QUADRAPLEGIA	
n.	SPASTIC DIPLEGIA	
o.	SPINA BIFIDA	
p.	TB SPINE	
q.	OTHER	

11. HOW OLD IS THE PERSON ? .....

12. HOW MUCH DOES THE PERSON WEIGH ? .....

C. CARING ACTIVITIES

13. WHICH OF THE FOLLOWING CARING ACTIVITIES ARE YOU INVOLVED IN AND HOW LONG DOES IT TAKE ?

		HOURS SPENT DAY	WEEK	MONTH	HELP NEEDED
a.	ACTIVITIES TO INCREASE THE INCOME				
b.	ASSISTING SOMEONE ELSE WITH LIFTING				
c.	ASSISTING AND LIFTING FOR TOILETING				
d.	ASSISTING WITH WALKING				
e.	BATHING				
f.	BRUSHING OF HAIR				
g.	BRUSHING OF TEETH				
h.	PUTTING IN A CATHETER				
i.	CHANGING SANITARY TOWELS				
j.	CLEANING UP THE ROOM				
k.	COLLECTING THE GRANT				
l.	DRESSING				
m.	FEEDING				
n.	FETCHING THINGS FOR THE PERSON				
o.	GIVING AN INJECTION				
p.	GIVING MEDICATION				
q.	LETTER WRITING				
r.	LIFTING THE PERSON				

s.	LISTENING AND TALKING	
t.	MAKING TEA	
u.	MAKING SANDWICHES	
v.	MAKING TELEPHONE CALLS	
w.	OPENING DOORS	
x.	PLAY	
y.	PAYING ACCOUNTS	
z.	PREPARING MEALS	
aa.	PUSHING THE WHEELCHAIR	
ab.	SHOPPING FOR THE PERSON	
ac.	TURNING THE PERSON	
ad.	WASHING OF HANDS AND FACE	
ae.	WASHING OF PERSONS CLOTHES	
af.		
ag.		
ah.		
ai.		
aj.		

TOTAL

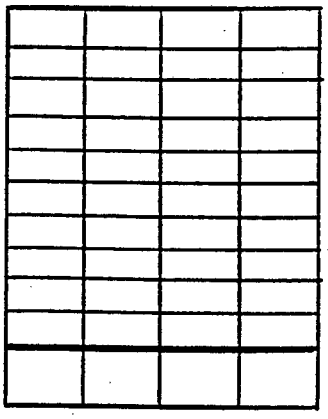
D. REPLACEMENT ACTIVITIES

14. WHICH OF THE FOLLOWING TASKS ARE YOU DOING THAT WOULD NORMALLY BE DONE BY THE DISABLED PERSON ?

		HOURS SPENT			HELP
		DAY	WEEK	MONTH	NEEDED
a.	ASSISTING CHILDREN WITH TOILETING				
b.	BATHING CHILDREN				
c.	BUDGETTING FOR THE FAMILY				
d.	CHANGING NAPPIES				
e.	CLEANING THE YARD				
f.	DRESSING CHILDREN				
g.	DRYING DISHES				
h.	DUSTING AND POLISHING FURNITURE				
i.	FEEDING CHILDREN				
j.	FETCHING CHILDREN FROM SCHOOL				
k.	HANGING UP THE WASHING				
l.	HELPING WITH HOMEWORK				
m.	IRONING				
n.	LOOKING AFTER YOUNGER CHILDREN				
o.	MAKING UP BEDS				
p.	PACKING THINGS AWAY				
q.	PAYING ALL ACCOUNTS				
r.	PREPARING LUNCH PACKS				
s.	PREPARING MEALS				
t.	SCRUBBING FLOORS				
u.	SETTING THE TABLE				
v.	SHOPPING				
w.	SUPPLEMENTING THE FAMILIES INCOME				
x.	SWEEPING THE FLOOR				
y.	TAKING THE WASHING OFF THE LINE				
z.	TAKING OUT THE DIRT				

aa. TAKING CHILDREN TO SCHOOL
ab. WASHING THE CAR
ac. WASHING CLOTHES
ad. WASHING DISHES
ae. WATERING THE GARDEN
af.
ag.
ah.
ai.
aj.

TOTAL



E. GENERAL

15. DID SOMEONE SHOW YOU HOW TO CARE FOR THE DISABLED PERSON ?

YES	NO

IF YES, PLEASE DISCUSS

.....

16. HOW LONG HAVE YOU BEING CARING FOR THE DISABLED PERSON ?

.....

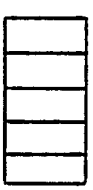
17. WHAT KIND OF HELP DO YOU NEED ?

REFER TO THE HELP COLUMNS ON PAGE 2, 3 AND 4

18. WHEN DO YOU DO YOUR SCHOOL HOMEWORK :

HOURS SPENT

a. IN THE MORNING BEFORE SCHOOL
b. IN THE AFTERNOON AFTER SCHOOL
c. IN THE EVENING AFTER SUPPER
d. WHILE AT SCHOOL
e. NONE OF THE ABOVE



IF e, PLEASE DISCUSS .....

.....

TO BE COMPLETED BY THE RESEARCHER

THE MOST CARING IS DONE BY .....

.....